

# Circadian Sleep Disorders Network



Presentation of our paper, entitled:

*Registry & Survey of Circadian Rhythm Sleep-Wake Disorder Patients*

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Alexandra Wharton, CSD-N Board Member

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Registry and survey of circadian rhythm sleep-wake disorder patients

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# Mission of Circadian Sleep Disorders Network



**CSD-N is an international patient advocacy non-profit established 12 years ago.**

**Its mission is to:**

- encourage research into circadian rhythm sleep-wake disorders
- increase awareness medical community / general public
- advocate for accommodations at work and school
- provide emotional support and treatment options

# CSD-N Highlights



- CSD-N board member on SDRAB – 2nd time
- Coalition partners with Project Sleep & Start School Later
- Represent at annual SLEEP conference 2023 and 2024

**Visit [csd-n.org](https://csd-n.org) to see our accomplishments**

# Circadian Rhythm Sleep-Wake Disorders



**Circadian rhythm sleep-wake disorders are defined as alterations in the sleep-wake cycle resulting from:**

- Changes to the underlying biological clock

**OR**

- Its ability to synchronize with the external environment



# Processes That Follow A Circadian Pattern



While the sleep-wake cycle is the most obvious output of the circadian clock, there are hundreds of biological processes that follow a circadian pattern.

Some of the more prominent rhythms known to be altered are melatonin, cortisol and core body temperature.



# CSD-N Created a Survey and Registry



Circadian rhythm sleep-wake disorders (CRSWDs) can have a devastating effect on the lives of those with these conditions.

In 2016, CSD-N created a patient survey and registry.

# Purpose of Survey and Registry



The purpose of the survey is to fill in knowledge gaps about these disorders including information on:

- Subjective patient experience
- Efficacy and durability of treatments

The purpose of the registry is to find volunteers who are willing to participate in research.

# Patients Solicited Worldwide



**Patients were solicited worldwide.**

The survey is in English - 87% of respondents live in five English-speaking countries.



# Invite Researchers to Analyze the Survey Data



**In the paper, we invite other researchers to analyze the survey data.**

It is possible other researchers will extract and publish conclusions of their own in the future.

# Respondent Information is De-Identified



**Respondents' information is de-identified.**

Respondents can be contacted by researchers only after they have given consent.

# Recruiting Participants



**The patient survey was promoted on our website and newsletter and across our social media channels:**

- X (formerly known as Twitter)
- Facebook
- Instagram
- LinkedIn



# Respondent Diagnosis Type



## Respondents Were Asked:

- Which CRSWD do they believe they have?
- Which has been formally diagnosed by a medical professional?

# Respondent Size



Of the 1627 people participated, 1298 completed the survey in its entirety.

To avoid questions about whether self-diagnosed patients properly diagnosed themselves ...

... we present results based on the 479 respondents who were clinically diagnosed.

# Survey Questionnaire



The survey consists of 122 questions about the patients' experiences with their disorders.

To see questions, go to our website and search on 'survey questions,' or navigate directly to [www.circadiansleepdisorders.org/registry/survey\\_questions.php](http://www.circadiansleepdisorders.org/registry/survey_questions.php)



# Survey Covers Variety of Topics



## Relating to:

- Diagnosis
- Tiredness
- Work Impact
- Comorbidities
- Treatments

# Sample Questions



- If left to your body's natural schedule, what time would you typically fall asleep ... and typically wake up?
- Have you ever applied for accommodations at work because of your disorder?
- Do other family members have a CRSWD?



# RESULTS

Many of our findings contradict common assumptions among researchers and clinicians; others lend support to or expand on hypotheses in the field.



# CRSWD Subtypes



**Of the 479 respondents:**

- **82%** (391) had Delayed Sleep-Wake Phase Disorder
- **21%** (101) had Non-24-Hour Sleep-Wake Rhythm Disorder
- **5%** (26) had Irregular Sleep-Wake Rhythm Disorder
- **1%** (7) had Advanced Sleep-Wake Phase Disorder

# Diagnosis Challenges



**‘Difficulty obtaining a diagnosis’ was a very common response:**

- 24% of patients took 10+ years to receive accurate diagnosis
- 77% were misdiagnosed initially, many with multiple incorrect diagnoses over the years

# Diagnosis Challenges



**Chief among these incorrect diagnoses:**

- Depression
- Insomnia
- No diagnosis at all (selected 'Doctor said nothing is wrong')



# Tiredness



Another common response regarded the connection between abnormal sleep timing and tiredness.

It has been asserted that tiredness in CRSWDs only occurs when sleep is reduced by attempting to sleep at a time not consistent with the patient's circadian rhythms (**against their body clock**).

# Tiredness



**However, when sleeping on what respondents believed was their body's natural schedule, more than half of the participants reported tiredness.**

On average, respondents sleeping on their preferred schedule felt they needed 8.7 hours of sleep.

25% of respondents need 10 or more hours of sleep to function adequately.

# Tiredness



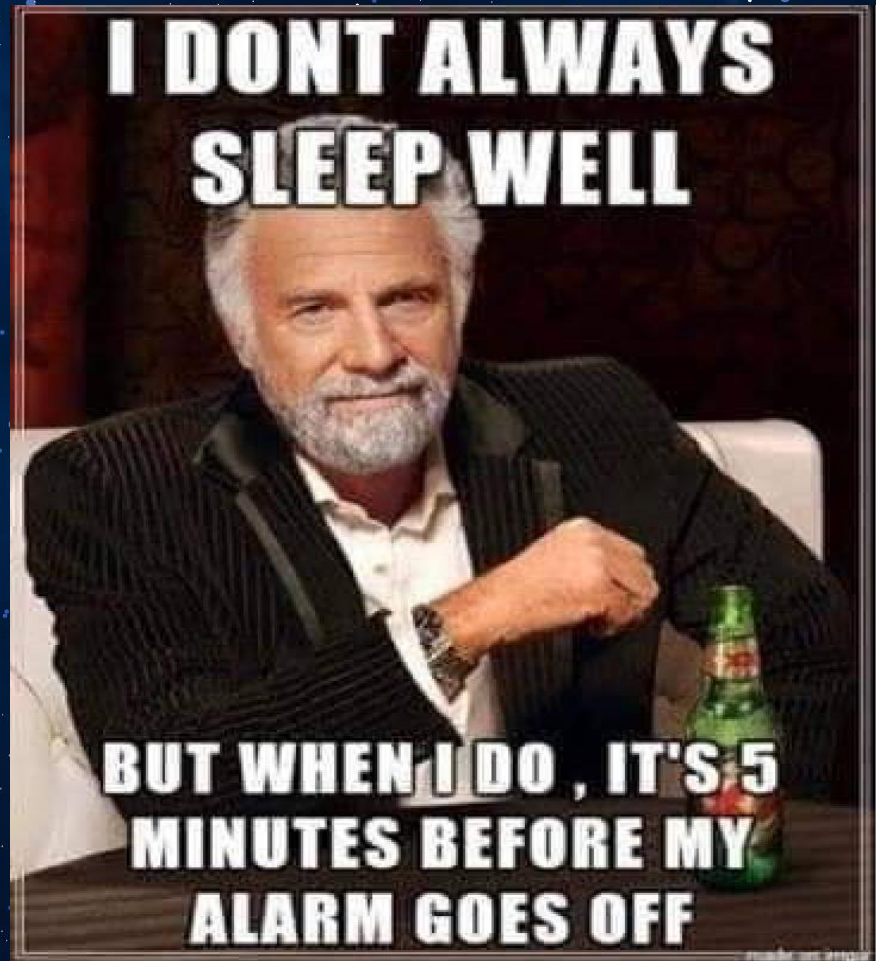
**This set of findings suggests a complex interaction between circadian rhythms and tiredness. Possible reasons include:**

- An abnormality of circadian function leads to tiredness, which is not mitigated by sleeping at their natural time.
- Tiredness may result from desynchronization of the sleep-wake rhythm relative to other circadian processes. A loss of synchrony between different processes is a phenomenon termed 'dyschronism.'





# Work Impact



# Work Impact



**Of those who had to get up for work, school or family reasons:**

- the average sleep duration on workdays was 5.9 hours
- 61% got 6 hours or less of sleep on workdays

# Work Impact



63% were late for work or school **at least once a week**, which could have a significant impact on their job and academic performance and evaluation.



# CO-MORBIDITIES



- Depression
- Other Sleep Disorders
- Sensitivity to Bright Light
- Migraines

# CO-MORBIDITIES – Depression



**58% of respondents also suffered from depression**

Of those 58%, 57% reported their depression started *AFTER* their CRSWD had developed.

This suggests that the arrow of causality is more often in the other direction, with circadian differences / lack of sleep leading to depression.

# CO-MORBIDITIES – Depression



## Possible Reasons:

- Biological Effect\*\* – cites paper University of Pittsburgh 2016.

*\*\*Evidence from pre-clinical and clinical research provides an undeniable link between disruptions in the circadian clock and the development of psychiatric diseases, including mood and substance abuse disorders.*

- Psychological Struggle against feeling tired all the time.



# CO-MORBIDITIES – Depression



- **Social Factors** - These conditions greatly interfere with work, school and social life – causing loneliness and isolation – often to the point of disability.
- **Little Empathy** - This may be particularly true where the disorder is not well understood and the patient is often blamed for what is outside of their control.

# CO-MORBIDITIES – Other Sleep Disorders



**51% of respondents had also been diagnosed with another sleep disorder, most commonly:**

- Bruxism
- Apnea
- Restless Leg Syndrome - reported to have circadian aspects

The presence of other sleep disorders could contribute to diagnostic delay.

# CO-MORBIDITIES – Sensitivity to Bright Light



**46% of respondents felt they were unusually sensitive to bright light.**

Some hypothesize that sensitivity to the phase-shifting effect of light is an etiological factor in DSWPD.



# CO-MORBIDITIES – Migraines



**26% of our participants reported migraines.**

Studies have connected photophobia and light-induced migraines to the same ipRGC cells that perform the light-sensing role in regulating circadian rhythms.

# TREATMENTS



- Light Therapy
- Light Restriction
- Melatonin
- Phase-Delay Chronotherapy

# TREATMENTS – Light Therapy



Of the 55% of respondents (263 people) who tried light therapy:

- 30% are still using it
- Only 26% said it helped somewhat or more
- Only 13% said they achieved their desired sleep times



# TREATMENTS – Light Therapy



**There are some limitations in interpreting this result.**

We do **not** know how light therapy was prescribed, or the degree of compliance.

Nevertheless, these results would seem to suggest a substantial number of patients for whom light treatment is not efficacious.

# TREATMENTS – Light Therapy



The American Academy of Sleep Medicine, in their practice guidelines, found that there was NOT sufficient evidence to recommend light treatment for either DSWPD or Non-24.

# TREATMENTS – Light Restriction



**Of the 48% of respondents (228 people) who tried light restriction / avoidance of evening light,**

- 59% are still using it
- 32% said it helped somewhat or more

Evening light restriction fares a bit better than morning light exposure but the rate of success was still dismayingly low.



# TREATMENTS – Melatonin



**Of the 81% of respondents (386 respondents) who tried melatonin,**

- Only 37% are still using melatonin
- Only 12% said they achieved their desired sleep times

**Melatonin was by far the most commonly attempted treatment but had a very poor success rate in terms of patient satisfaction.**

# TREATMENTS – Phase-Delay Chronotherapy



**The most disturbing results concerns the use of phase-delay chronotherapy as a treatment for DSWPD.**

This regimen involves the patient delaying their sleep more each night – typically by 3 hours a night – until their sleep shifts to a more desirable wake time.

# TREATMENTS – Phase-Delay Chronotherapy



Of the 51% of DSWPD patients who tried phase-delay chronotherapy:

- only 1% said it succeeded indefinitely
- 95% said it helped for a month or less or not at all



# TREATMENTS – Phase-Delay Chronotherapy



**Of the respondents who tried phase-delay chronotherapy:**

- 11% subsequently received a clinical diagnosis of Non-24
- 26% believe their DSWPD became Non-24 after using it

Many of these respondents never went back to the doctor who recommended the chronotherapy treatment since it had such a disastrous result for them, so they didn't have an opportunity for formal diagnosis of the Non-24.

# TREATMENTS – Phase-Delay Chronotherapy



The low success rate and the high risk suggest that even 30 years after researchers first published the risks of phase-delay chronotherapy, it is not widely recognized.

**This puts many patients in danger of progressing to Non-24.**

# Sighted Non-24



- **21% (101) of respondents had Non-24**
- All of our respondents are sighted
- We find that more people suffered from Sighted Non-24 than some of the literature would lead us to expect.
- We believe the etiology of Sighted Non-24 is different than Blind Non-24.



# Survey Currently Open



Data for this study was collected between December 1, 2016 and August 18, 2022.

The survey and registry are currently still open to respondents.

# In Conclusion



By collecting information from a large number of people suffering from CRSWDs, we hope to stimulate research into the causes, treatments and effects of circadian rhythm sleep-wake disorders.

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