



# Circadian Sleep Disorders Network

Advocating for people with misaligned body clocks

*csd-n.org*

## Some Preliminary Survey Results

for Circadian Rhythm Sleep Disorders

*talk by*

*Peter Mansbach, PhD*

*President, Circadian Sleep Disorders Network*

*[peter@csd-n.org](mailto:peter@csd-n.org)*



# Circadian Sleep Disorders Network

Advocating for people with misaligned body clocks

*csd-n.org*

## Registry and Survey

[www.CircadianSleepDisorders.org/registry](http://www.CircadianSleepDisorders.org/registry)

- Provide study subjects with characteristics of interest
  - De-identified
- Survey: 123 questions
  - [www.CircadianSleepDisorders.org/registry/survey\\_questions.php](http://www.CircadianSleepDisorders.org/registry/survey_questions.php)
- Preliminary results:
  - [www.CircadianSleepDisorders.org/registry/survey\\_results\\_prelim.php](http://www.CircadianSleepDisorders.org/registry/survey_results_prelim.php)
- More info:
  - [www.CircadianSleepDisorders.org/info/registry.php](http://www.CircadianSleepDisorders.org/info/registry.php)
  - My email: [peter@csd-n.org](mailto:peter@csd-n.org)

Registry and Survey conducted in partnership with AltaVoice (formerly Patient Crossroads), a wholly owned subsidiary of Invitae Corp.



# Circadian Sleep Disorders Network

Advocating for people with misaligned body clocks

*csd-n.org*

## Preliminary Results

- 208 completed surveys as of May 28, 2017
- Looked only at totals
- Did not eliminate bogus entries
- Did not investigate correlations or breakdown

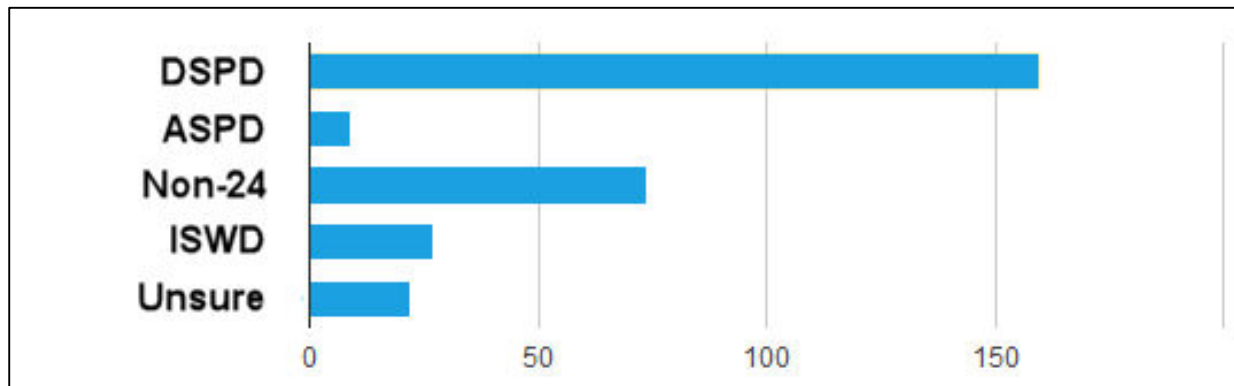


# Circadian Sleep Disorders Network

Advocating for people with misaligned body clocks

*csd-n.org*

## Circadian Rhythm Disorders



<b>DISORDER:</b>	<b>Number</b>	<b>% Diagnosed</b>
Delayed Sleep Phase Disorder	150	61%
Advanced Sleep Phase Disorder	9	11%
Non-24-Hour Sleep-Wake Disorder	69	36%
Irregular Sleep-Wake Disorder	26	23%



# Circadian Sleep Disorders Network

Advocating for people with misaligned body clocks

*csd-n.org*

## Tiredness

- Sleeping on body's preferred schedule:
  - 58% still feel tired
  - 32% sleep 9½ hours a night or more
  - *Comment: contradicts the belief that sleep would be perfectly normal if we slept on our own schedule*
- Forcing oneself up for work, school, family:
  - 53% get 6½ hours of sleep a day or less
  - 61% are late to school/work at least once a week



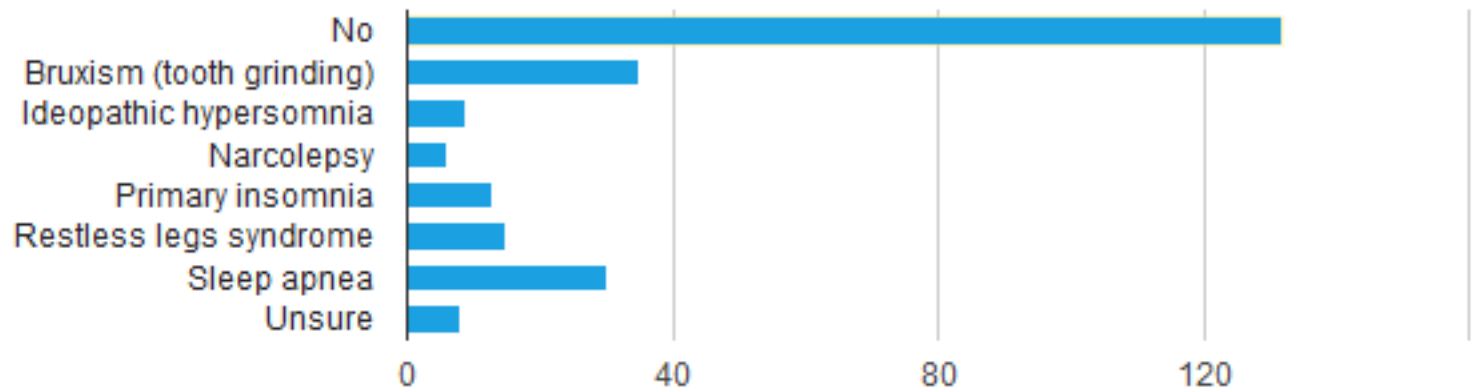
# Circadian Sleep Disorders Network

Advocating for people with misaligned body clocks

*csd-n.org*

## Other Sleep Disorders

Have you ever been correctly diagnosed with any other sleep disorder? (Select all that apply.)



- 37% of respondents with a circadian rhythm disorder also have been correctly diagnosed with another sleep disorder  
*Comment: Many patients have multiple symptoms, which can complicate diagnosis and treatment.*



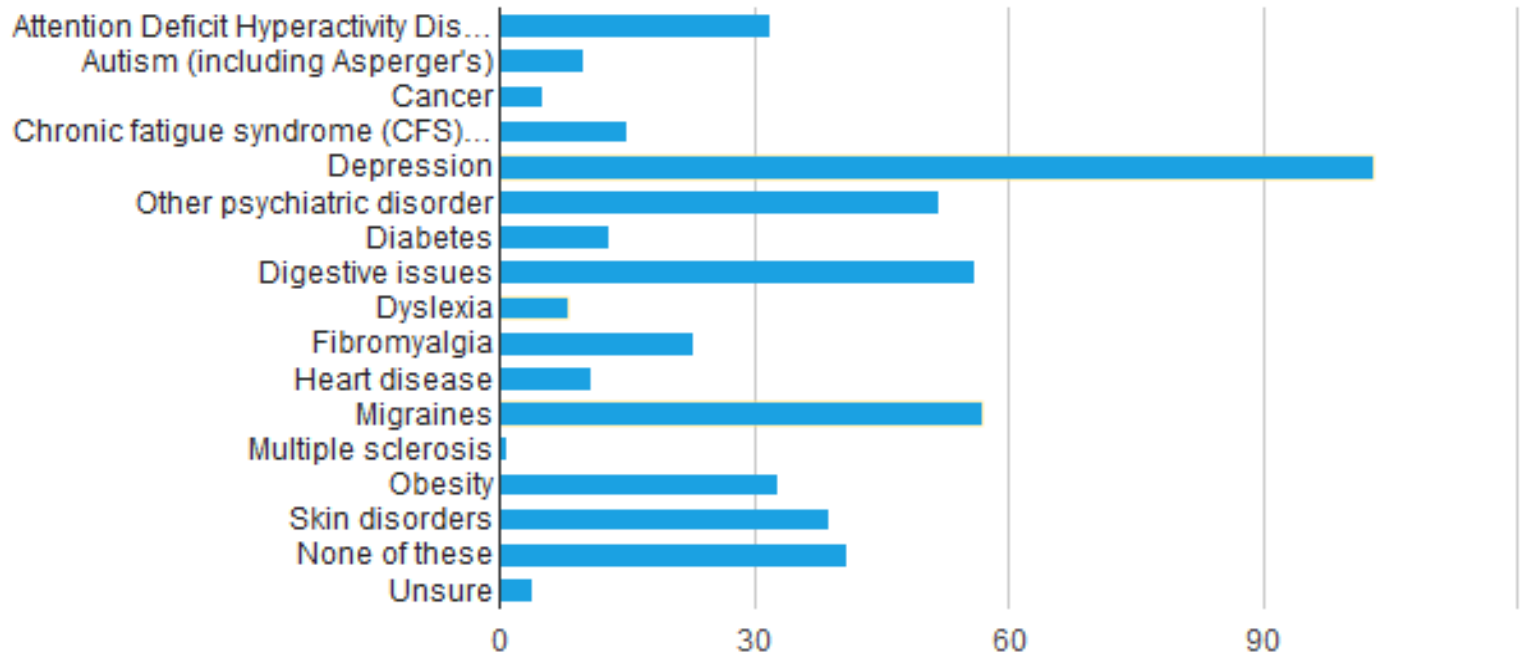
# Circadian Sleep Disorders Network

Advocating for people with misaligned body clocks

*csd-n.org*

## Other Conditions

Have you ever been correctly diagnosed with any of the following conditions?  
(Select all that apply.)





# Circadian Sleep Disorders Network

Advocating for people with misaligned body clocks

*csd-n.org*

## Other Conditions

- 47% also suffer from depression. For 2/3 of those, the depressions started after the circadian rhythm disorder. *Comment: Doctors frequently say that depression is the cause of sleep problems. This suggests it is often the other way around.*
- 26% also get migraines.
- 49% of respondents felt they were unusually sensitive to bright light. *Comment: Is this sensitivity related to response to various treatments?*





# Circadian Sleep Disorders Network

Advocating for people with misaligned body clocks

*csd-n.org*

## Treatments

Treatment	Number who tried	%still using	Comments
Light Therapy	80	29%	Only 18% achieved desired sleep times. 25% said it helped somewhat or more.
Light Restriction	75	62%	38% said it helped somewhat or more. 23% said it helped a little.
Melatonin	140	36%	Only 13% achieved desired sleep times. Most used it within an hour of bedtime.
Phase-delay chronotherapy	68	n/a	Only 1 helped indefinitely. <b>29% became Non-24 after using.</b>



# Circadian Sleep Disorders Network

Advocating for people with misaligned body clocks

*csd-n.org*

## NIH Web Site

- **Five years!!!**
- At least half a dozen pages list
  - Sleep Apnea
  - Restless Legs
  - Narcolepsy
  - Insomnia
- **No mention of Circadian Rhythm Sleep Disorders**



# Circadian Sleep Disorders Network

Advocating for people with misaligned body clocks

*csd-n.org*

## NIH Web Site Examples

### No mention of Circadian Rhythm Sleep Disorders:

- on the NHLBI Sleep Disorders Information web page  
[www.nhlbi.nih.gov/health/public/sleep/index.htm](http://www.nhlbi.nih.gov/health/public/sleep/index.htm)
- in the NHLBI Diseases And Conditions Index  
[www.nhlbi.nih.gov/health/health-topics/by-alpha/](http://www.nhlbi.nih.gov/health/health-topics/by-alpha/)
- in the NINDS web page section Sleep Disorders  
[www.ninds.nih.gov/disorders/brain\\_basics/understanding\\_sleep.htm#sleep\\_disorders](http://www.ninds.nih.gov/disorders/brain_basics/understanding_sleep.htm#sleep_disorders)
- on the NICHD What Are Some Common Sleep Disorders? page  
[www.nichd.nih.gov/health/topics/sleep/conditioninfo/pages/sleep-disorders.aspx](http://www.nichd.nih.gov/health/topics/sleep/conditioninfo/pages/sleep-disorders.aspx)
- in the NHLBI Your Guide To Healthy Sleep  
[www.nhlbi.nih.gov/health/public/sleep/healthy\\_sleep.pdf](http://www.nhlbi.nih.gov/health/public/sleep/healthy_sleep.pdf)
- NCSDR Participating Organizations page (CSD-N not listed)  
[www.nhlbi.nih.gov/about/org/ncsdr/patpub/partorgs.htm](http://www.nhlbi.nih.gov/about/org/ncsdr/patpub/partorgs.htm)



# Circadian Sleep Disorders Network

Advocating for people with misaligned body clocks

*csd-n.org*

## Registry and Survey Links

[www.CircadianSleepDisorders.org/registry](http://www.CircadianSleepDisorders.org/registry)

- Survey: 123 questions
  - [www.CircadianSleepDisorders.org/registry/survey\\_questions.php](http://www.CircadianSleepDisorders.org/registry/survey_questions.php)
- Preliminary results:
  - [www.CircadianSleepDisorders.org/registry/survey\\_results\\_prelim.php](http://www.CircadianSleepDisorders.org/registry/survey_results_prelim.php)
- More info:
  - [www.CircadianSleepDisorders.org/info/registry.php](http://www.CircadianSleepDisorders.org/info/registry.php)
- My email: [peter@csd-n.org](mailto:peter@csd-n.org)

Registry and Survey conducted in partnership with AltaVoice (formerly Patient Crossroads), a wholly owned subsidiary of Invitae Corp.



# Circadian Sleep Disorders Network

Advocating for people with misaligned body clocks

*csd-n.org*

*Thank You!*

**Visit us at: [CircadianSleepDisorders.org](http://CircadianSleepDisorders.org)**

***shortcut: [csd-n.org](http://csd-n.org)***

***(don't forget the hyphen!)***

***Email me at: [peter@csd-n.org](mailto:peter@csd-n.org)***



# Circadian Sleep Disorders Network

Advocating for people with misaligned body clocks

*csd-n.org*

## Treatments

Have you seriously tried (regularly used) any of the following treatments for your circadian rhythm sleep disorders? (Select all that apply.)

