Some Preliminary Survey Results

for Circadian Rhythm Sleep Disorders

talk by
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Registry and Survey

www.CircadianSleepDisorders.org/registry

• Provide study subjects with characteristics of interest
  – De-identified

• Survey: 123 questions

• Preliminary results:

• More info:
  – My email: peter@csd-n.org

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

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Number</th>
<th>% Diagnosed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delayed Sleep Phase Disorder</td>
<td>150</td>
<td>61%</td>
</tr>
<tr>
<td>Advanced Sleep Phase Disorder</td>
<td>9</td>
<td>11%</td>
</tr>
<tr>
<td>Non-24-Hour Sleep-Wake Disorder</td>
<td>69</td>
<td>36%</td>
</tr>
<tr>
<td>Irregular Sleep-Wake Disorder</td>
<td>26</td>
<td>23%</td>
</tr>
</tbody>
</table>

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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
Other Sleep Disorders

• 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.*
Other Conditions

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

- Attention Deficit Hyperactivity Disorder
- Autism (including Asperger's)
- Cancer
- Chronic fatigue syndrome (CFS)
- Depression
- Other psychiatric disorder
- Diabetes
- Digestive issues
- Dyslexia
- Fibromyalgia
- Heart disease
- Migraines
- Multiple sclerosis
- Obesity
- Skin disorders
- None of these
- Unsure
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?
# Treatments

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

No mention of Circadian Rhythm Sleep Disorders:

• on the NHLBI Sleep Disorders Information web page
• in the NHLBI Diseases And Conditions Index
  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
• on the NICHD What Are Some Common Sleep Disorders? page
  www.nichd.nih.gov/health/topics/sleep/conditioninfo/
  pages/sleep-disorders.aspx
• in the NHLBI Your Guide To Healthy Sleep
• NCSDR Participating Organizations page (CSD-N not listed)
  www.nhlbi.nih.gov/about/org/ncsdr/patpub/partorgs.htm
Registry and Survey Links

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Thank You!

Visit us at: CircadianSleepDisorders.org
shortcut: csd-n.org
(don't forget the hyphen!)

Email me at: peter@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.)

- None
- Light therapy
- Light restriction (includes use of...
  - Melatonin
  - Helloci (tasimelteon)
  - Rozerem (ramelteon)
- Valdoxin (agomelatine)
- Xyrem (sodium oxybate)
- Sleeping pills
- Alcohol or street drugs
- Prescription stimulant medications
- Other medication
- Phase-delay chronotherapy (shift...
- Diet
- Other natural remedies