

# TALK FOR NARCOLEPSY NETWORK CONFERENCE 2013: Circadian Rhythm Sleep Disorders and Narcolepsy

---

Note: The slides for this talk may be viewed at

<http://www.circadiansleepdisorders.org/docs/talks/NNconf2013talkSlides.pdf> .

Slides with audio of the talk are at <http://youtu.be/i70SqjCr-iY> .

## I. Introduction [title slide]

### A. Hello

Hi. I'm Peter Mansbach, and I'm president of Circadian Sleep Disorders Network. I'm really glad for this opportunity to talk about circadian sleep disorders, and also about possible connections with narcolepsy.

### B. Disclaimer

Let me start by saying I am not a medical doctor. I don't diagnose, and I don't treat.

### C. Why should the narcolepsy community care? [Overview slide]

The various sleep disorders overlap. I have DSPS, but I have some of the same symptoms as narcolepsy. And many of you have symptoms of DSPS. Diagnoses are fuzzy too, and in some cases another sleep disorder may be secondary or even dominant. I'll talk more about this later.

### D. Intro

How many of you have trouble waking up in the morning? How many of you like to stay up late?

## II. Circadian Rhythm Sleep Disorders

### A. What are circadian rhythms? [slide]

#### 1. General

Circadian means "approximately a day". Circadian rhythms are processes in living organisms which cycle daily. They are produced internally in all living things.

They are also referred to as *the body clock*.

#### 2. In Humans

Humans have internal cycles lasting on average about 24 hours and 10 minutes, though the length varies from person to person. (Early experiments seemed to show a cycle of about 25 hours, and this still gets quoted, but it is now known to be incorrect. It arose because those experiments allowed light exposure

in the evening.) While these internal rhythms are approximately 24 hours, they are adjusted daily by external factors, called *zeitgebers*, especially sunlight or other bright lights. This synchronizing with the 24 hour day/night cycle is called *entrainment*.

The most noticeable feature of circadian rhythms is the sleep/wake cycle. But there are other circadian rhythms including swings in many hormones throughout the day, the body temperature cycle, appetite and the times of best alertness and productivity. Ideally these rhythms are in sync with each other and with the light-dark cycle in nature. Most folks are awake during daylight hours and sleep during darkness.

The master clock in the body is a small part of the brain called the suprachiasmatic nucleus (SCN), located in the hypothalamus. (You remember the hypothalamus, right? That's where hypocretin is also produced.) The SCN keeps the clocks within organs and individual cells in the body in sync. The master clock normally gets adjusted every day when a person is exposed to light. The receptors in the eye most effective in doing this are not the rods and cones we learned about in school, that give us vision. They are cells called ipRGC cells (intrinsically photosensitive retinal ganglion cells), which are not involved in vision, and were discovered not so long ago.

## **B. What are circadian rhythm sleep disorders? [slide]**

The length of the internal circadian cycle can normally be a bit shorter or longer than 24 hours. In normal sleepers the cycle is *entrained* to the day/night cycle by external factors, especially light. If it cannot be entrained, the result is a circadian disorder.

So a Circadian Rhythm Sleep Disorder is an abnormality of the body's internal clock, in which a person is unable to fall asleep at a normal evening bedtime, although he is able to sleep reasonably well at other times dictated by his internal rhythm.

The person cannot fall asleep when desired, so he complains of insomnia. He has trouble waking up when desired, so he complains of excessive sleepiness. It takes some insight to make the connection with the timing of sleep rather than the sleep itself.

In addition to the sleep/wake cycle, the internal coordination of the various other rhythms may also be faulty. For example, some hormones may be on a different daily cycle than others, and this lack of coordination between systems may produce other symptoms in addition to the sleep disorder.

Common to these disorders is inflexibility: even when physically tired or sleep deprived, sufferers cannot make up for lost sleep outside of their hard-wired sleep times. This factor is generally misunderstood by people who do not suffer from these disorders, leading to a conclusion that we are just lazy or haven't tried hard enough to live on society's schedule.

Some people are flexible and can adjust to sleeping on practically any schedule. Still, they may prefer to wake up early (such people are often called "larks") or stay up late ("night owls"). But other people cannot adjust, and forcing themselves to be awake at the wrong time for their body can make them ill.

## C. CRSD Subtypes [slide]

The *International Classification of Sleep Disorders Revised* (ICSD-R) lists 6 subtypes of circadian rhythm sleep disorder:

- Delayed Sleep-Phase Syndrome
- Non-24-Hour Sleep-Wake Disorder
- Advanced Sleep-Phase Syndrome
- Irregular Sleep-Wake Pattern
- Shift Work Sleep Disorder
- Jet Lag Syndrome

Note that “Jet Lag Syndrome” and “Shift Work Disorder” refer to disorders (severe cases) of jet lag or shift work, not all instances of these. Newer classifications omit jet lag disorder, since it is temporary.

We’ll focus mainly on Delayed Sleep-Phase Syndrome and Non-24-Hour Sleep-Wake Disorder.

## D. DSPS

### 1. ICSD-R Definition [slide]

(Don’t read this!)

- Sleep-onset and wake times that are intractably later than desired
- Actual sleep-onset times at nearly the same daily clock hour
- Little or no reported difficulty in maintaining sleep once sleep has begun
- Extreme difficulty awakening at the desired time in the morning, and
- A relatively severe to absolute inability to advance the sleep phase to earlier hours by enforcing conventional sleep and wake times.

### 2. Definition

Delayed Sleep-Phase Syndrome (or Delayed Sleep-Phase Disorder) is a disorder in which a person’s sleep occurs much later than desired. He finds it difficult to impossible to fall asleep until very late at night, and therefore difficult to wake up until very late in the morning or even afternoon.

### 3. Example [slide diagram]

For example, a normal sleeper may sleep from 11pm to 7am. Someone whose sleep is delayed six hours (as an example) would be sleeping from 5am to 1pm. This makes it impossible to hold a typical 9 to 5 job. If the person tried to hold the job anyway, but still couldn’t fall asleep till 5am, he would quickly become severely sleep deprived.

### 4. TWO factors [slide]

Why not just go to bed earlier? There are TWO factors involved in DSPS: one is that the body’s clock is shifted later in the day; the other is that the person is unable to shift it earlier. He either cannot sleep at an earlier time at all, or his sleep is not restorative.

It's similar with shift work: some shift workers can adjust to working at night and sleeping during the day. Some have difficulty. Some cannot adjust at all.

### **5. Hard to understand**

This is REALLY HARD for a person with normal sleep to understand. They can fall asleep when they are tired. They get tired when they're supposed to. They may have trouble getting up on time, or they may feel tired, but then they can get to sleep earlier the next night. It is really difficult for most people to understand what we're up against.

### **6. Biological markers [slide]**

There are a number of biological markers that can be measured, that cycle with the circadian rhythm. So we can objectively measure a person's CR, and confirm that there really is something physical going on, it's not just a matter of being lazy.

Melatonin is a hormone produced by the body, which is intimately involved with sleep. It's level normally rises about two hours before bedtime (called Dim Light Melatonin Onset, or DLMO), is high during the night, and falls toward morning. In people with DSPS, melatonin secretion is delayed, or in some cases non-existent.

Core body temperature normally drops around bedtime, reaches a minimum [*nadir*] a few hours before awakening, and then rises again. Core body temperature is also delayed in people with DSPS.

Cortisol also follows a circadian rhythm.

### **7. My junior year, my diagnosis**

Let me tell you about some of my own experiences.

[slide] In college I had trouble getting up on time for class. My roommate junior year threatened to go to the dean because I kept snoozing my alarm, seven, eight, nine times. I was unaware that I was even doing that.

But who knew about sleep disorders? A lot of people complained about hating to get up in the morning. So I just forced myself to do so. I was young.

[slide] That year I had to take the earliest class of my college career. I had an hour between classes, and I was so tired that I would lie down in the corridor outside the next classroom and nap. If you're tired enough, you don't care how weird you look.

I also started having migraines during that class, but didn't make the connection with the early rise time.

I wouldn't be diagnosed until 16 years later. Sound familiar?

[slide] Even that was a stroke of luck. Back then, there weren't any sleep labs in the Washington DC area, where I lived. So I was referred to Montefiore hospital's sleep lab in New York. Quite by chance, at that time the research team there was first elucidating DSPS. Their paper wouldn't be published for another year. But they recognized the disorder in me immediately.

Since then I've lived on my natural schedule. But I did lose my physics job, and my career in research, because of my hours. Fortunately I could find contract work in computer programming, which I could do on a later schedule. My sleep time now is roughly 3 am to noon.

While I was living on society's schedule I had two episodes of major depression, and was always a bit down [dysthymia]. Since I've lived on my body's preferred schedule, I've had no more episodes of depression, and a pretty normal mood.

## **8. Other stories**

I read letters from our members with DSPS. Here are some quotes from different people:

[slide] "For decades I worked day jobs after sleeping 3:30 to 7:30 a.m., catching up on weekends.... That worked while I was young and resilient. Next step was adding a "nap" 5 to 10 p.m. Wreaks havoc with the social life, but it kept me my job for years.

"If you can't be normal, you're not good enough. You learn to apologize, make excuses, tell lies. No one understands. "

[slide] "I just can't help thinking that I'd have no problem being awake and alert if I were to simply follow my own natural sleep cycle. The only problems I would face are unemployment and nearly no social life."

## **E. Others (ASPS, ISWD, shift work disorder) [slide]**

Advanced Sleep-Phase Syndrome (ASPS) is the opposite of Delayed Sleep-Phase Syndrome: people fall asleep early in the evening, and wake up very early in the morning, perhaps 4am. It is much rarer than DSPS, according to the Norwegian study. People who suffer from it get up early, get to work on time, and don't generally need to sleep until after normal work hours. So their lives are not disrupted as much, compared with DSPS or Non-24 people.

I don't know much about Irregular Sleep-Wake Disorder . It is very rare. It occurs mostly in people with severe brain dysfunction.

## **F. Non-24**

### **1. Definition [slide diagram]**

Non-24-hour Sleep-Wake Disorder (Non-24) is a disorder in which an individual falls asleep later each day. Generally the delay is about an hour or two, corresponding to a "day" that's 25 - 26 hours long; but it can be much longer. Their body's preferred sleep times progress around the clock.

It's also known as Free-Running Disorder, and hypernycthemeral syndrome.

### **2. Example**

[diagram] For example, let's suppose our subject goes to sleep today when she is tired at midnight and sleeps till 8am, and is fine. Tomorrow, she may not be tired enough to fall asleep until 2 in the morning, and so she'd need to sleep till 10. The next day she can't fall asleep till 4am, and she sleeps till noon. So

it progresses: a few days later she'll be going to sleep at noon, and some time after that, at 6pm. Her sleep progresses all the way around the clock, back to where it started, and keeps going like that.

### **3. In blind people**

It is estimated that over half of all totally blind individuals suffer from non-24. That's at least 75,000 Americans. This is not surprising, given that people synchronize their slightly longer circadian rhythms to the 24 hour day through light exposure, and the totally blind aren't getting that light exposure through vision. Some do respond to light exposure via ipRGC cells, which are separate from vision; others do not.

### **4. In sighted people**

Non-24 is believed to be rare in sighted individuals, but that is not known for certain. Certainly it is rarely diagnosed. Yet I know of over 50 sighted individuals with non-24.

### **5. Living with Non-24**

Some non-24 folks, especially those unaware of the condition, force themselves to live on a 24 hour schedule. When their body's preferred sleep time coincides with the earth's night, they sleep well and feel fine during the day. When their body's preferred sleep time falls during the daytime, they sleep poorly and suffer excessive daytime sleepiness. This makes their problem look like periods of insomnia, with some good nights clustered together in between. So it is difficult to recognize the non-24 as such, and as a result non-24 is almost certainly underdiagnosed.

Other people "go with the flow", and sleep and wake as their body dictates. They are sometimes in sync with the day/night cycle, but their sleep progresses around the clock, later and later each day. They find it impossible to hold any conventional job, and difficult to have a social life.

For some, the delay is regular. For example, they may shift an hour later each day. But for others the delay varies, up to several hours, and they cannot predict their schedule at all. So it becomes difficult to schedule any appointments in advance

### **6. Personal Stories**

I read letters from our members with Non-24, and it breaks my heart. Many of these folks cannot find a job, and have no money. Here are some quotes from different people:

[slide] "It's so frustrating not to be able to predict even one day in advance when I will be awake. Sure there is an overall vague 26-28 hour rhythm; but superimposed on that is this huge random element. Sudden unexpected bouts of insomnia at a time I thought I would sleep. Sudden overwhelming tiredness when I thought I would be awake. Everything is out of sync. My body is like an orchestra out of tune and with no conductor."

[slide] "Ever since I became Non-24, I constantly have to beg people to change their schedules, or try to be pleasing and unobtrusive while I quietly ask if they have another time available. It's affected my relationships with all: family, who don't believe it in it; friends, who can never find a slot to talk to me, let alone get together, and, have all finally stopped trying; doctors, next to impossible to schedule....

When I can't meet the world's demands, I am deemed selfish or weak or lazy or depressed.... I am fine with me. But the world is not fine with me, and that makes me not fine.

I feel so isolated; I'm desperate for social contact."

[slide] "What is hardest is explaining non-24 to new acquaintances, for example someone you might meet at a party. It tends to derail the whole social process. The inability to remain employed has an even more profound effect on my social life. It's not something people accept when you look healthy."

## **G. Incidence (how many affected) [slide]**

How many people have DSPS (and are not just evening types by preference)? Based on a Norwegian study, 0.17% of ADULTS have this disorder. That's about 3 in 2000, or half a million American adults. About 3 times as many people as have narcolepsy! (But we need more data.)

But most go undiagnosed.

It's more common in teens. Estimates of perhaps 7 – 10% of teens are common. That's around 2,000,000 Americans. But most grow out of it.

Non-24 is found in over half of totally blind people, so at least 75,000 Americans. It has rarely been diagnosed in sighted individuals, as discussed earlier, but we know of quite a few.

## **H. Causes [slide]**

I believe there are several different abnormalities that can cause Circadian Rhythm Sleep Disorders (CRSDs). These may include:

- lack of sensitivity to light
- over-sensitivity to light
- long intrinsic circadian period
- lack of melatonin production
- long elimination time of melatonin
- deficiencies in the light-sensitive ipRGC cells of the retina
- long time from core temperature minimum to wake up time
- differences in tolerance to phase mismatch, etc.

It's my belief that both DSPS and Non-24 have similar underlying causes. They differ in the degree of various factors, and how they interact, with the result that DSPS people can entrain to a 24 hour day (though not at the usual time), and non-24 people cannot. I know of several people who used to have DSPS, but are now Non-24.

## **I. Treatment [slide]**

### **1. Sleeping pills (no help)**

Sleeping pills are often prescribed by GPs, but they are of little help. They make you unconscious, but don't alter your circadian rhythm, and the resulting sleep is not restorative

## **2. Chronotherapy (risky)**

Since most people with DSPS find it difficult to move their schedule earlier, the original treatment had patients moving their schedule later instead, an hour later each day all the way around the clock until they reached their desired wake up time. Then they were supposed to stabilize. Even when successful, it has a high rate of relapse and has to be repeated frequently. But for some, their sleep times kept progressing: their DSPS had become Non-24, a much more disruptive disorder. So this could be a risky treatment.

## **3. Light Therapy**

The most common treatment for circadian rhythm disorders is light exposure. It has been shown that light in the morning advances the rhythm (makes it earlier), whereas light in the evening delays it. So for both DSPS and Non-24, the light must be used in the morning. And it has to be bright. The common recommendation is 10,000 lux for at least half an hour. That's very bright: typical room lighting in a home runs between 50 and 100 lux. Sunlight is great. There are now a number of light boxes made for this purpose.

Some people are helped by this. Others, not so much.

## **4. Light Restriction (“Dark Therapy”)**

Recent research indicates that even low levels of light in the evening can delay the clock. So, it takes a really bright light in the morning to advance the clock, but only moderate light in the evening to delay it. Blue light has a particularly strong effect. It is thought that the bluish light from TV, computers, and phones may be delaying the rhythms even of normal sleepers.

So some people are now trying to restrict light in the evening, including using blue-blocking glasses, and have reported some success with shifting their schedule this way. But there are no standards yet regarding how much light is tolerable, how early the restriction should start, and whether light without blue content is ok to use during dark time.

## **5. Melatonin**

Melatonin is a hormone produced by the body, which is intimately involved with sleep. It's level normally rises about two hours before bedtime, is high during the night, and falls toward morning.

Melatonin has been used to treat circadian rhythm disorders in two ways, which unfortunately get confused. Some people take it shortly before bedtime, and it helps them fall asleep [hypnotic]. Others take it 4 – 6 hours before. Used in this way, it can help advance their rhythm [chronobiotic]. But it can also make them sleepy too early.

This treatment seems especially useful for blind people, since they don't have the option of using bright light in the morning. Several pharmaceutical companies have developed melatonin agonists as an alternative to melatonin itself.

## **J. Research issues [slide]**

### **1. Multiple underlying causes**

We mentioned several possible causes earlier. The studies of treatments done to date do not distinguish between these various causes.

I would conjecture, for example, that for people who are not sensitive enough to light, very bright light in the morning is what works. For those super-sensitive to light, light restriction in the evening (sometimes called "dark therapy") is key.

We need research into the specific underlying causes of circadian rhythm disorders, and into tailoring the various treatments to the underlying causes.

### **2. Therapy parameters**

We need more specific guidance on parameters – what time should light be used? What time should dark therapy commence? What time melatonin? How bright (and what color) should the lights be? How dark (and what color) the dark period? How much melatonin?

We need these parameters to be determined by studying patients with these disorders, not just normal sleepers.

We need data on how often treatment succeeds in practice, including the combination of light and dark therapy. Success to us is not only laboratory measurements (e.g. shifts in melatonin timing), but subjective improvement. These don't always correlate.

For example, researchers often measure Dim Light Melatonin Onset, or DLMO, as a marker of circadian rhythm. They claim success with treatment if DLMO has shifted. Yet some people report still feeling tired on the new regimen, and often abandon treatment. To put it bluntly, I don't care if my DLMO has shifted, if my head is still in a fog all day.

### **3. Better tests for easier diagnosis**

We need simpler and cheaper tests to measure the biological markers.

We'd all love a test that objectively measures tiredness.

### **4. Incidence**

Our estimates of how often these disorders occur are based on very spotty research. Some researchers believe we greatly underestimate the prevalence. We need better surveys, which must involve better diagnosis.

### III. Relationships to Narcolepsy [slide]

#### A. Common theme of daytime sleepiness

People with Circadian Rhythm Sleep Disorders who continue to live on a normal daytime schedule become severely sleep-deprived, and have many of the same symptoms of excessive daytime sleepiness as PWNs.

#### B. Common experiences

I recently listened to a number of PWNs testify at the FDA hearing. I was struck by the similarities in our stories:

- So many bright people with career aspirations that were stopped in their tracks by their sleep disorders;
- So many people unable to get suitable accommodations at work;
- So many people who went for years being repeatedly misdiagnosed, and often given medications, with side effects, for conditions they didn't have;
- So many unwarranted referrals to mental health professionals;
- So much misunderstanding by society, even by families.

We're often told we could get up early if we wanted. We show the doctors articles on the web, research articles in the journals, but *they refuse even to look at them*. They just refer us to the psychiatrists.

#### C. The Myth of the good night's sleep

When you read in the journals about Circadian Rhythm Sleep Disorders, you often read that if permitted to sleep during our bodies' preferred times, our sleep would be fine, and we would awaken alert. But for many of us this is not so. We may not sleep well, we may awaken often during the night, and we feel tired and even dysfunctional in the morning.

A friend of mine with sleep apnea told me the same thing: yes, his CPAP machine helped some, but he was still tired all the time.

I hear this from folks with narcolepsy, too: the meds help, but we still struggle, we still feel tired, we still need naps.

It seems to be a common theme with many of these sleep disorders, that even with treatment, we're still tired, we still struggle. Clearly, there is still a lot we don't understand. There are disruptions in sleep architecture that are not explained by a single diagnosis. It is likely that there are overlapping sleep disorders in some cases.

#### D. Lots of PWNs seem to be evening types, or even DSPS

I've attended the last two Narcolepsy Network conferences and talked with a number of PWNs. It seems like most of the people I talked with prefer to go to bed late at night, and don't like to get up in the morning. (The exception, of course, is those on xyrem.) In some cases, people have told me that they cannot fall asleep before the wee hours.

So I wonder, is there a connection between narcolepsy and delayed sleep phase? I'm not aware of any reports of this in the literature. But so little is understood about the underlying causes of DSPS, that perhaps there are some common factors. Or do some of us have both disorders? We need more research!

### **E. Possibility of narcolepsy being misdiagnosed (really DSPS)**

There is also another possibility: that narcolepsy may in some cases be misdiagnosed.

Narcolepsy without cataplexy has some symptoms similar to sleep deprivation, especially the excessive daytime sleepiness and the sudden irresistible urge to fall asleep during the day. The boundaries between sleep and wake are blurred. Nighttime sleep may be fragmented.

Dr Mignot has noted that workers on a night shift may test positive on an MSLT, even though they test normal when working on a daytime schedule. This is because their internal circadian rhythms are out of sync with respect to the hours they're trying to sleep. One might expect, therefore, that someone with DSPS living on a daytime schedule would also test positive on an MSLT, since his rhythms are similarly out of sync.

[and see <http://www.ncbi.nlm.nih.gov/pubmed/14592363>: Clinical caveat: prior sleep deprivation can affect the MSLT for days. Janjua T, et al.]

With the efforts of the Narcolepsy Network and others, most doctors are now aware of narcolepsy, and many sleep doctors are able to recognize it. But so many are still unaware of DSPS, or think it occurs only in teens; unaware of non-24, or think it occurs only in blind folks. So they send the patient for an MSLT, get the positive result, and diagnose narcolepsy.

It seems possible that at least some people diagnosed with narcolepsy w/o cataplexy may in fact have Delayed Sleep Phase Disorder as their primary disorder.

[the following paragraph was not in the talk as originally written. I've added it since in response to a listener's question:]

What does this mean for treatment? If a circadian disorder is suspected, I would think it appropriate to live on your body's preferred schedule for a while. That may reduce daytime sleepiness to where it may not be necessary to treat it with medication, or where less medication may be sufficient. If it is then desired to shift one's schedule to a time more in sync with society, it would be appropriate to try the treatments for circadian rhythm sleep disorders that we discussed - light and dark therapy and melatonin. Even if medication for narcolepsy is still needed, one might feel more alert and energetic as a result of having dealt with the circadian rhythm aspect.

## **IV. Circadian Sleep Disorders Network**

### **A. Need [mission slide]**

Most people have not heard of DSPS or Non-24. Our friends and families did not believe these were real disorders. Even sleep specialists often did not recognize the disorders, or believed that they were easily treatable. Patients could not get accommodations at work or school.

We needed an organization to raise awareness. Two years ago we formed Circadian Sleep Disorders Network.

### **B. Mission**

Circadian Sleep Disorders Network is a nonprofit organization dedicated to improving the lives of people with chronic circadian rhythm disorders.

We aim to increase awareness within the medical community and among the general public, to provide emotional support and practical ideas for people living with these disorders, to encourage research into circadian rhythms, and to advocate for accommodations in education and employment for people with circadian rhythm sleep disorders.

### **C. Similarities in our organizational goals [slide]**

We need to raise awareness, among doctors, school personnel, employers, and the public. We need to get accommodations for people with these disorders, at work and at school. We need more research to understand the causes and to improve treatment.

Sound familiar? Narcolepsy Network has the same goals. But you're 25 years ahead of us!

By now most doctors have at least heard of narcolepsy. Time to diagnosis has decreased. The public is increasingly aware of the disease. Most schools will provide some accommodations, and increasingly workplaces do also.

That is not yet the case for circadian rhythm sleep disorders.

### **D. Sleep is not taken seriously - we're all working on this**

Further, sleep isn't valued in our culture. People pride themselves on how little sleep they need, and many people routinely get 1 or 2 hours less sleep than they need. Those of us who argue for getting sufficient sleep are too often ignored. We need to work together to change this.

### **E. Sleep disorders are not taken seriously - we're all working on this**

People often respond to those of us who are sleep deprived by saying "Oh, I'm feeling tired too" or "Gee, I hate to get up in the morning too - but I do." As you guys know only too well, there is a difference between being "a little tired" and being so tired that you can hardly function.

### **F. CSDs not well known, not referenced even on sleep websites**

Circadian rhythm sleep disorders are not well known. One area where we have made an effort to increase awareness is on the web. Many sleep organizations have websites that list sleep disorders, but

don't include DSPS or Non-24. Some that do have misinformation. Others insist these disorders are easy to treat.

We've written to a number of websites which have links to sleep organizations, and gotten our name and website added. I'm happy to say Narcolepsy Network was the first of those!

### **G. Some other awareness projects we've done/are doing [slide]**

- We have a web site with extensive information and links at [csd-n.org](http://csd-n.org). **And don't forget the hyphen**, or you'll get the Chinese Software Development Network!
- We have several brochures, both printed and on our web site (and on display here at the conf)  
[below is on slide, but not in talk:]
- We have a Facebook page and a LinkedIn page.
- We've approached other sleep web sites and gotten them to link to ours.
- We've asked our members to give our brochures to their doctors.
- One member got a series of 5 articles on DSPS published on Salary.com
- We got Non-24 listed on NORD (National Organization of Rare Diseases). But DSPS is too common – it is not considered rare.
- We've joined in the Sleep Walk in DC
- I've spoken at several meetings on sleep.
- We even have T-shirts, mugs, and bumper stickers available from CafePress.

### **H. Things are starting to change**

20 years ago hardly anyone had even heard of circadian rhythms. Now many have. Research is being done on the best time of day to take medication, for example for cancer. Some people are aware that there are associated sleep disorders.

20 years ago I needed special permission to get a fasting blood test at 2 pm. Today they still look at me questioningly, but at least they accept my statement that my body is really on a later schedule.

We need more awareness, more accommodation, more research. And people to help us get there. We're just getting started.

### **I. Thank you [slide]**

Thank you.

Please visit our web site at [csd-hyphen-n.org](http://csd-hyphen-n.org)