

VIEWPOINT

Divided autism community bonds over need to study sleep

BY **SARA LUTERMAN**

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The autism community is deeply divided on many topics — whether to describe autism as a difference or a disorder, whether ‘autistic’ is a better term than ‘person with autism,’ and how much genetics and the environment each contribute to the condition, to name just a few. But there is one thing we agree on: We need more research on sleep.

On 4 May, I spoke on a panel at the headquarters of the U.S. Food and Drug Administration (FDA) in Rockville, Maryland. At the meeting, industry representatives, advocates — including myself — and parents of autistic children talked about issues pertaining to autism treatments.

As at most such autism meetings, tensions were high at times: Autistic adults, self-advocates like me and parents of autistic children don’t always see eye to eye. I rolled my eyes as one woman claimed with conviction that autism is an autoimmune disorder and that megadoses of vitamins had cured her son. I’m sure some parents rolled their eyes during my comments — I went to college, so what could I know about real autism?

But something remarkable happened during the final open-discussion period. The room seemed to light up as parents and self-advocates alike talked about autism and problems with sleep. This is something with which we all struggle.

Also astonishing? The utter lack of research on autism and sleep. A PubMed search reveals nine

clinical trials on autism and sleep in the past five years. Compare that with the more than 400 clinical trials of treatments for core autism features, such as social deficits, published over the same period. This is absurd given the demonstrable need for solutions to sleep problems in autistic people: Difficulties with sleep are at least twice as common in autistic people as in the general population.

If the goal of autism research is to improve the lives of those of us on the spectrum, scientists pursuing this work need to turn their attention to trouble with sleep — and its many connections to health, mood and behavior.

Sleepless nation:

A variety of sleep problems plague people across the spectrum. One friend of mine from college has such severe Non-24-hour sleep-wake disorder — an irregular or reversed sleep-wake cycle — that she is unable to hold down a regular job, despite being exceptionally bright. Another friend has taken to living in his van to try to better regulate his sleep cycle with natural light.

Personally, I have never had a good night's sleep. I often have difficulty falling asleep. I have profuse night sweats, to the point that I've had to get a mattress protector. I grind my teeth so badly in my sleep that I once broke a filling.

Sleep difficulties also profoundly affect the parents and caregivers of autistic people, especially those with high support needs. If someone needs supervision and he's awake at 3 a.m., his caregiver has to be up, too. I'm sure many neurotypical parents of autistic children miss normal sleep dearly. We are all exhausted.

At the FDA meeting, parents described their children's sleep problems, and self-advocates talked about their own. We then spontaneously came together to call for better pharmaceutical options to address sleep problems.

I have tried a laundry list of drugs, ranging from mild over-the-counter supplements such as melatonin to heavier hypnotics such as Ambien. Melatonin made me feel hungover. Ambien made me do utterly bizarre things I didn't remember the next day. One morning I woke up and found I had made an e-mail account for my childhood dog. That was the last time I tried taking a prescription drug for sleep.

I tried cognitive behavioral therapy and found it helpful for falling asleep, but it did not improve my sleep quality. And it's useless for anyone whose problem is waking up multiple times a night or an abnormal sleep cycle. I use a weighted blanket, which helps a little, although the **single study** on whether this is an effective sleep aid for autistic people concluded that it doesn't do anything. A weighted blanket may just be my preferred placebo.

Unanswered questions:

There is almost certainly a difference between sleep problems in autistic people and neurotypical people, but we don't know much about that. We also need to know why many drugs metabolize differently in autistic people.

In non-autistic people, sleep issues are frequently associated with mood disorders such as depression and anxiety, and these disorders are more common among autistic people. We need to know whether sleep disruption in autistic people contributes to their high rates of depression and anxiety or is a result of those conditions.

Sleep deprivation also undoubtedly makes us all more irritable. And might poor sleep contribute to the intensity of sensory sensitivities and issues with attention?

There are many unanswered questions. I make this appeal to scientists and the organizations that fund them: Please commit to looking for answers.

Sara Luterman is founder of NOS Magazine, the first online news and culture site by and for the neurodiversity community.