

# STUDY SHOWS FAMILIES PREFER MULTIDISCIPLINARY CARE FOR NARCOLEPSY

## Children's Mercy Researcher Surveys Youth, Parents and Sleep Physicians

### INCIDENCE OF PEDIATRIC NARCOLEPSY AND COMORBIDITIES

Narcolepsy is a lifelong neurological disorder characterized by excessive daytime sleepiness, cataplexy, sleep-related hallucinations and sleep paralysis.

Typical onset of this condition may occur anytime between the ages of 10 and 20, with the peak age of identification around 15 years old. Some researchers believe that narcolepsy is under-diagnosed in children.<sup>1</sup>

While there are medications to treat narcolepsy, these patients may have substantial medical and psychological comorbidities. In children, comorbidities include rapid weight gain, precocious puberty and a significant burden of illness related to mental health and school performance.

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### WAKE UP NARCOLEPSY FUNDS PEDIATRIC STUDY

David Ingram, MD, a pediatric sleep specialist and researcher with Children's Mercy Kansas City and a board member for the advocacy organization Wake Up Narcolepsy, along with Lindsay Jesteadt, PhD, Claire Crisp and Stacey Simon, PhD, conducted a study to report on the primary challenges of youth, parents and physicians related to narcolepsy; assess perception of clinical care; and elicit feedback regarding the ideal configuration of care.

Their research was recently published in the *Journal of Clinical Sleep Medicine* and was funded by Wake Up Narcolepsy.<sup>2</sup> They utilized the organization's database to conduct an anonymous internet survey of children/adolescents ages 12-22, parents of children with narcolepsy and sleep physicians. Separate youth, parent and provider versions of the survey included both multiple-choice and open-ended questions.

### YOUTH AND PARENTS IDENTIFY CHALLENGES

In all, 35 youth and 116 parents completed the surveys. Youth and parents rated these symptoms as the most common and problematic:

1. Daytime sleepiness
2. Disturbed nighttime sleep
3. Mood difficulties

Youth and parents identified these primary psychosocial concerns as substantial challenges:

1. Difficulty focusing/memory
2. Difficulty with schoolwork
3. Worry/anxiety

Youth and parents commonly reported these behavioral strategies related to narcolepsy:

1. Scheduled bedtime/wake time
2. Daytime naps
3. Exercise and diet

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### PHYSICIANS CITE DIFFERENT CONCERNS

Thirty sleep medicine physicians completed the same survey. Interestingly, the study identified a contrast between concerns for youth/parents and physicians, with physicians citing medication side effects and getting a driver's license as the greatest challenges for their patients. Physicians found the most used and helpful medications to be traditional stimulants, sodium oxybate and modafinil/armodafinil.

## PREFERENCE FOR MULTIDISCIPLINARY CARE

Despite the significant medical and psychiatric comorbidities associated with narcolepsy, traditionally, most pediatric hospitals provide care for these patients at individual specialist appointments, rather than in a multidisciplinary clinic setting.



*Dr. Ingram's research showed the need for a multidisciplinary approach to care, lending support to a biopsychosocial framework for pediatric narcolepsy.*

As part of this research, Dr. Ingram and his colleagues set out to determine if this care model is meeting the needs of pediatric narcolepsy patients and their families, eliciting feedback regarding the ideal configuration, features, services and structure of state-of-the-art family-centered care.

Their findings were consistent with a recent survey of patients with hypersomnia, which suggests that a sizeable proportion of patients' symptoms are not managed by medications alone. More than 90% of patients utilize nonpharmacologic therapies.<sup>3</sup>

Specific findings of Dr. Ingram's survey included:

- Youth and parents preferred clinic visits every three to four months in a multidisciplinary clinic including nursing, psychology and nutrition, lending support for a biopsychosocial framework in caring for pediatric narcolepsy patients.
- Additional resources from support groups, family education days and family retreats were also highly rated as potentially beneficial.

## INVESTIGATING TREATMENT EFFECTIVENESS

Based on this research, the Children's Mercy Sleep Center has developed a Narcolepsy Pre-Visit Clinic Worksheet that patients and families complete before their appointment. This allows the patient and family to list all their concerns so the team can address them efficiently.

Dr. Ingram and his colleagues also are in the process of completing a second stage of this research focused on treatment. Important aspects addressed include medications and lifestyle modifications, such as sleep hygiene, diet and exercise. Dr. Ingram anticipates this study will be published in an academic medical journal in 2021.

In addition, the Children's Mercy team is considering establishing a multidisciplinary narcolepsy clinic, with patient visits integrating sleep specialists, a behavioral psychologist, nutrition services and social work rather than scheduling separate appointments.

### REFERENCES

- <sup>1</sup> Wake Up Narcolepsy website: <https://www.wakeupnarcolepsy.org/about/what-is-narcolepsy/>. Accessed June 26, 2020.
- <sup>2</sup> Perceived Challenges in Pediatric Narcolepsy: A Survey of Parents, Youth, and Sleep Physicians. Ingram D, Jesteadt L, Crisp C, Simon SL. *Journal of Clinical Sleep Medicine*. September 8, 2020. doi: doi.org/10.5664/jcsm.8774.
- <sup>3</sup> Behavioral Sleep Medicine Services for Hypersomnia Disorders: A Survey Study. Neikrug AR, Crawford MR, Ong JC. *Behavioral Sleep Medicine* 15(2):1-14. January 2016.

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