



Raising Awareness of Narcolepsy Through Stakeholder Research and Media Relations

Narcolepsy, a lifelong neurological sleep disorder characterized by the brain's inability to regulate sleep-wake cycles, has been poorly understood, underfunded and challenging to diagnose.¹ To speed up narcolepsy diagnoses, [Wake Up Narcolepsy](#) (“WUN”), a U.S. nonprofit and patient advocacy organization based outside of Boston, was formed to promote awareness and research into narcolepsy, and more recently, raise awareness of the Pediatric Hypersomnolence Survey (“PHS”). The PHS is a screening tool developed by researchers at Boston Children’s Hospital that can be used to assess sleepy kids and teens.²

SITUATION

FTI Consulting’s Strategic Communications segment supported WUN in a pro bono capacity to educate specialty and generalist physicians about narcolepsy and to raise awareness of the PHS. Professionals from the segment’s Healthcare & Life Sciences and Digital & Insights teams engaged stakeholders in an online quantitative survey, which sought to better understand perceptions around narcolepsy and the diagnostic challenges faced by clinicians.

OUR ROLE

- Alongside WUN’s leadership, FTI Consulting surveyed 100 practicing, specialty and generalist physicians – including sleep specialists, psychiatrists, pediatricians, neurologists, pulmonologists and general practitioners – in Greater Boston who diagnose or test pediatric narcolepsy to assess physician awareness and sentiment.
- The team developed a press release for WUN to disseminate across its platforms highlighting the survey results’ key findings and insights.
- FTI Consulting created a targeted media relations strategy to raise awareness of the effects in coordination with World Narcolepsy Day and WUN’s Northeast Narcolepsy Conference.

“With the research in-hand, WUN looks forward to building upon existing work and to continue shaping future advocacy, educational and treatment initiatives so children with narcolepsy and their loved ones do not have to wait years for a diagnosis.”

— Monica Gow, Co-Founder and Executive Director, Wake Up Narcolepsy

OUR IMPACT



FTI Consulting dedicated more than 130 hours to support WUN in raising awareness for narcolepsy and the PHS.



[Survey results](#) were leveraged to create a foundation of communications materials for WUN, enabling the organization to develop additional communications strategies to support its mission of improving narcolepsy awareness, diagnosis and treatment.



Through targeted media outreach and existing reporter relationships, FTI Consulting was able to secure coverage of the results in publications such as the *Worcester Business Journal*.



Finally, survey results gained social media attention from key stakeholders across major platforms, including LinkedIn, Twitter (now ‘X’), Instagram and Facebook, and continue to be used in collateral that helps educate practitioners on narcolepsy.

1. <https://www.wakeupnarcolepsy.org/about/what-is-narcolepsy/>

2. <https://www.wakeupnarcolepsy.org/news/boston-childrens-hospital-pediatric-hypersomnolence-survey/>

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