



## **Survey Findings Highlight the Burden of Neurogenic Orthostatic Hypotension (nOH) on Patients and Care Partners**

*Symptoms of nOH may affect approximately one in five people with Parkinson's Disease*

Deerfield, Ill., September 24, 2018 – Results from a nationwide survey highlighting patient and care partner perception of the impact and burden of neurogenic orthostatic hypotension (nOH) and its symptoms point to the need for heightened education and awareness of nOH.<sup>1</sup> In the survey publication in [BMC Neurology](#), the authors noted that, “to the best of our knowledge, our study is the first to investigate the impact of nOH from both the patient and caregiver perspective.”<sup>1</sup> The survey was developed by Lundbeck through a partnership with The Michael J. Fox Foundation for Parkinson's Research and three neurologists who specialize in the care of movement and/or autonomic disorders: Daniel Claassen, MD, PhD, Associate Professor of Neurology at Vanderbilt University, Charles Adler, MD, PhD, Professor of Neurology at Mayo Clinic College of Medicine, and Dr. Christopher Gibbons, MD, Associate Professor of Neurology at Harvard Medical School.

nOH is defined as a sustained drop in blood pressure upon standing that is due to autonomic dysfunction and is often associated with an underlying neurodegenerative disorder, such as Parkinson's disease.<sup>2,3</sup> Symptoms of nOH may include dizziness, lightheadedness, fatigue, blurred vision and others that occur upon standing.<sup>3</sup> The survey was conducted online by Harris Poll. A total of 363 patients and 128 care partners, also known as caregivers, were surveyed, and 90 percent of patients self-identified as diagnosed with Parkinson's disease.<sup>1</sup>

Most of the patients (87 percent) and care partners (95 percent) surveyed said that nOH symptoms had an overall negative impact on patients' ability to perform certain daily activities.<sup>1</sup> Additionally, more than 40 percent of patients and 59 percent or more of care partners reported that patients had reduced or stopped activities such as physical activity/exercise, housework, and hobbies because of symptoms of nOH.<sup>1</sup>

“This survey reinforces what I hear from my patients with orthostasis related to nOH. Given the challenges of disease management, especially in Parkinson's Disease, where patients have many complex medical issues, orthostatic symptoms are not always addressed in the clinical visit, despite their burden,” said Dr. Daniel Claassen, Associate Professor of Neurology at Vanderbilt University and one of the study authors. “Patients need to know that orthostatic symptoms related to autonomic dysfunction can be managed and should be discussed with their healthcare provider.”

Fifty-five percent of patients and care partners somewhat or strongly agreed that patients did not initiate a discussion about their nOH symptoms with their healthcare provider unless the symptoms were severe.<sup>1</sup> In addition, 60 percent of patients somewhat or strongly agreed that they often hide or minimize their nOH symptoms.<sup>1</sup> Fifty percent of patients surveyed somewhat or strongly agreed that nOH symptoms made them feel anxious or worried.<sup>1</sup>

“Non-motor symptoms can impact a person’s activities and daily life,” said Rachel Dolhun, MD, Vice President of Medical Communications at The Michael J. Fox Foundation for Parkinson’s Research. “People should know neurogenic orthostatic hypotension can be part of Parkinson’s, and it’s important to discuss their symptoms with their doctor.”

“The compelling insights from this survey helped us gain a more intimate understanding of the difficulties faced by patients and care partners,” said Arthur Hewitt, PhD, Lundbeck Senior Scientific Advisor, Neurology, and one of the study authors. “Lundbeck will leverage this understanding to provide better education and support for this challenging condition.”

For information about nOH, please visit [www.nOHMatters.com](http://www.nOHMatters.com) and [www.facebook.com/nOHMatters](https://www.facebook.com/nOHMatters).

### **About the Survey**

The authors designed a closed-ended, multiple choice set of questions related to patient nOH symptomatology and perception of disease burden. The survey was conducted online by Harris Poll between August 26, 2016 and Oct 3, 2016 on behalf of Lundbeck. Patient organizations including The Michael J. Fox Foundation for Parkinson’s Research, American Parkinson Disease Association, Davis Phinney Foundation, MSA Coalition, National Parkinson Foundation, and Parkinson’s Disease Foundation helped to recruit patients for the US-based survey. Survey respondents included 363 patients and 128 care partners, and primary diagnosis of Parkinson’s disease was self-selected in 90 percent of patients. In addition, 10 percent of patients reported multiple system atrophy and 4 percent reported pure autonomic failure. Similar rates of patient diagnosis were reported by care partners. Despite meeting survey criteria, a formal diagnosis of OH or nOH was reported by 36 percent of patients. This study represents the views of a limited sample of nOH patients and may not be representative of all patients with nOH. Other limitations of this study include that care partners were not required to be paired with patients included in the survey, so it is not possible to draw conclusions regarding the consistency of responses between patients and their care partners.<sup>1</sup>

### **About Neurogenic Orthostatic Hypotension (nOH)**

nOH is caused by inadequate release of norepinephrine upon standing and is due to autonomic dysfunction often associated with an underlying neurodegenerative disorder, such as Parkinson’s disease.<sup>2,3</sup> This may result in an inability for a person to maintain adequate blood pressure and blood flow to the brain upon standing, which can result in various symptoms such as dizziness, lightheadedness, fatigue, blurred vision, and others.<sup>3</sup> Approximately one in five people with Parkinson’s may experience symptoms of nOH.<sup>4</sup>

### **About Lundbeck**

Lundbeck is a global pharmaceutical company specialized in psychiatric and neurological disorders. For more than 70 years, we have been at the forefront of research within neuroscience. Our key areas of focus are depression, schizophrenia, Parkinson’s disease and Alzheimer’s disease.

Our approximately 5,000 employees in more than 50 countries are engaged in the entire value chain throughout research, development, production, marketing and sales. Our pipeline consists of several late-stage development programs and our products are available in more than 100 countries. Our research center is based in Denmark and our production facilities are located in Denmark, France and Italy. Lundbeck generated revenue of DKK 17.2 billion in 2017 (EUR 2.3 billion; USD 2.6 billion).

In the U.S., Lundbeck employs approximately 900 people focused solely on accelerating therapies for brain disorders. With a special commitment to the lives of patients, families and caregivers, Lundbeck

U.S. actively engages in hundreds of initiatives each year that support our patient communities. A recognized leader in patient-centricity, Lundbeck was ranked first among 30 companies in overall corporate reputation by U.S. patient groups in 2015, 2016 and 2017 according to PatientView survey results. For additional information, we encourage you to visit our corporate site at [www.lundbeckus.com](http://www.lundbeckus.com) and connect with us on Twitter at @LundbeckUS.

## References

1. Claassen, D. Adler, C. Hewitt, L. Gibbons, C. Characterization of the Symptoms of Neurogenic Orthostatic Hypotension and Their Impact From a Survey of Patients and Caregivers. *BMC Neurology*. 2018;18:125.
2. Freeman, R. Consensus statement on the definition of orthostatic hypotension, neutrally mediated syncope and the postural tachycardia syndrome. *Clin Auton Res*. 2011;21:69-72.
3. Freeman, R. Clinical practice. Neurogenic orthostatic hypotension. *The New England Journal of Medicine*. 2008;358(6):615-24.
4. Ha, A. The prevalence of symptomatic orthostatic hypotension in patients with Parkinson's disease and atypical parkinsonism. *Parkinsonism Relat Disord*. 2011;Sep;17(8):625-8.

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