



## Parkinson & Movement Disorder (PMD) Alliance and Neurocrine Biosciences Announce New Survey Results Revealing the Significant Impact OFF Time Has on People with Parkinson's Disease and Their Care Partners

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- 86 percent of people with Parkinson's disease (PD) (n=113) taking the survey experience OFF time daily, and a majority report it has a significant impact on activities
- While three in four people with PD (78%) report that their current treatment plan is effective at limiting their PD symptoms, over half (56%) also say that they don't think their symptoms can improve beyond their current state

SAN DIEGO, Sept. 12, 2022 /PRNewswire/ -- Parkinson & Movement Disorder (PMD) Alliance, in partnership with [Neurocrine Biosciences](#) (Nasdaq: NBIX), a leading neuroscience-focused biopharmaceutical company committed to meeting the needs of people with complex and debilitating disorders, today announced results from the *Survey Assessment: Impact of OFF Time on People with Parkinson's Disease and Their Care Partners*. Findings revealed that despite a majority of these people with Parkinson's disease (PD) and their care partners being significantly impacted by OFF time—a period of time when PD symptoms return between regular doses of carbidopa/levodopa medication—there is a general acceptance that the emergence of OFF time is part of the disease, and they may not be aware of the availability and use of adjunctive treatment options to address return of PD symptoms.



The survey was conducted by Ipsos, one of the largest market research and polling companies globally.

"At PMD Alliance, we are passionate about connecting directly with the PD community about their experiences, challenges, and strategies to live well after a diagnosis. We hear again and again about the impact of OFF time, from both people living with the disease, and their loved ones and care partners," said Andrea Merriam, Acting CEO, PMD Alliance. "Good communication between families and healthcare providers is crucial to recognize the signs of OFF time and stay informed about adjunctive treatment options so intervention can occur early in the treatment plan, if needed."

Key findings from the survey include:

### **People with PD and Care Partners Should Discuss OFF Time Symptoms with a Healthcare Provider**

Among people with PD (n=113) taking the survey:

- 86 percent of these people with Parkinson's disease experience OFF time daily, and a majority report it has a significant impact on activities.
- While three in four people with PD (78%) report that their current treatment plan is effective at limiting their PD symptoms, over half (56%) also say that they don't think their symptoms can improve beyond their current state.

Among care partners (n=127) taking the survey:

- Care partners who took the survey are most likely to feel frustrated, anxious, and stressed when their loved ones with PD experience OFF time symptoms.

"The results of this survey reinforce that while numerous therapeutic options exist for our patients, these therapies may be under-utilized. We need to better explore what 'effective' means for each patient, and address what concerns may prevent them from seeking better symptom control," said Jill Farmer, DO, MPH, Assistant Professor of Neurology and Director of the Parkinson's Disease & Movement Disorder Program at the Global Neurosciences Institute in Lawrenceville, NJ. "It is our duty as physicians to make patients aware of available options for symptom improvement and when these options include medication, we need a thoughtful conversation about the potential benefits and risks of incorporating adjunctive therapy as part of their treatment plan."

### **Misconceptions About Adjunctive Therapy**

Among people with PD (n=113) taking the survey:

- Nearly all are willing to explore new treatment options (96%) and would ask their doctor about adjunctive therapies (94%).
- 72% of people with PD mistakenly believe that adding adjunctive therapy means their PD is progressing.
- Nearly half (49%) are unsure whether their current treatment plan is doing what it should, and 30% feel uninformed about additional treatment options.

Despite a majority of these people with Parkinson's disease and care partners being significantly impacted by OFF time, there is a general acceptance that the emergence of OFF time is part of the disease, and they may not be aware of the availability and use of adjunctive treatment options for use to address return of PD symptoms.

"Neurocrine Biosciences and PMD Alliance share an ongoing commitment to encourage greater awareness about the realities of living with PD, which includes how OFF time impacts people with PD and their care partners," said Olga Klepitskaya, Medical Director, Neurocrine Biosciences. "We're pleased to partner with PMD Alliance on this new initiative where our goal is to help foster discussions about OFF time treatment needs, including the potential benefits and risks of adjunctive therapy."

#### **About the Survey Assessment: Impact of OFF Time on People with Parkinson's Disease and Their Care Partners**

Conducted by Ipsos, the *Survey Assessment: Impact of OFF Time on People with Parkinson's Disease and Their Care Partners* included a sample of 240 adults (age 18+) from the continental U.S., Alaska, and Hawaii. Participants were interviewed online in English from May 5 through June 10, 2022. Of the patients who participated in a survey, 100 came from Ipsos' partner online panel source, M360, which specializes in conducting healthcare research using commercial panel sources. Another 13 interviews came from an email list obtained from the PMD Alliance. To qualify for the survey, respondents either needed to have received a clinical diagnosis of PD or be a primary care partner of someone with PD.

#### **About Parkinson's Disease**

Parkinson's disease (PD) is a chronic, progressive, and debilitating neurodegenerative disorder that affects approximately 1 million people in the U.S. and 6 million people worldwide. PD is associated with low dopamine levels produced in the brain. Dopamine helps transmit signals between the areas of the brain that control all purposeful movements, including talking, walking, and writing. As PD progresses, dopamine production steadily decreases, resulting in increased problems with PD symptoms including slowed movement (bradykinesia), tremor, rigidity, impaired posture and balance, and difficulty with speaking and writing.

There is presently no cure for PD and management of the disease largely consists of the use of treatments that attempt to control PD symptoms. The current gold standard for treatment of PD symptoms is carbidopa/levodopa. While carbidopa/levodopa improves patients' PD symptoms, as the disease progresses, the effects of levodopa begin to wear off more quickly. OFF time is when PD symptoms—such as stiffness or tremors—return between regular doses of medication. OFF time can happen when carbidopa/levodopa is wearing off. The way OFF time affects people with PD and the symptoms they experience are unique.

#### **About Parkinson & Movement Disorder (PMD) Alliance**

Parkinson & Movement Disorder (PMD) Alliance is an independent, national 501(c)3 nonprofit on a mission to empower people impacted by movement disorders with the tools and meaningful connections they need to thrive today. PMD Alliance provides free resources to the entire Movement Disorder Care & Support Ecosystem® —to people living with the disease, care partners and adult children, support group leaders, and healthcare providers—because we all do better when everyone's empowered. PMD Alliance believes in expanding access to high quality, expert-driven, deep-diving online and in-person programs. PMD Alliance is here to navigate the waves of a movement disorder together, bringing clarity and life-giving solutions.

PMD Alliance is not affiliated with any medical practice or institution.

Visit [PMDAlliance.org](https://www.pmdalliance.org) to learn more.

#### **About Neurocrine Biosciences**

Neurocrine Biosciences is a neuroscience-focused, biopharmaceutical company with a simple purpose: to relieve suffering for people with great needs, but few options. We are dedicated to discovering and developing life-changing treatments for patients with under-addressed neurological, neuroendocrine, and neuropsychiatric disorders. The company's diverse portfolio includes FDA-approved treatments for tardive dyskinesia, Parkinson's disease, endometriosis\* and uterine fibroids\*, as well as over a dozen mid- to late-stage clinical programs in multiple therapeutic areas. For three decades, we have applied our unique insight into neuroscience and the interconnections between brain and body systems to treat complex conditions. We relentlessly pursue medicines to ease the burden of debilitating diseases and disorders, because you deserve brave science. For more information, visit [neurocrine.com](https://www.neurocrine.com), and follow the company on [LinkedIn](#), [Twitter](#) and [Facebook](#). (\*in collaboration with AbbVie).

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#### **Forward-Looking Statements**

In addition to historical facts, this press release contains forward-looking statements that involve a number of risks and uncertainties. These statements include, but are not limited to, statements regarding the potential benefits to be derived from the Company's products and product candidates, the Company's plans to encourage awareness that may help address the needs of people living with PD, and the value that such awareness may bring to patients. Among the factors that could cause actual results to differ materially from those indicated in the forward-looking statements are: risks and uncertainties associated with the commercialization of the Company's products or product candidates; risks that the Company's products and/or product candidates

may be precluded from commercialization by the proprietary rights of third parties, or have unintended side effects or adverse reactions or incidents of misuse; risks and uncertainties relating to competitive products and technological changes that may limit demand for the Company's products; risks associated with potential generic entrants for our products; risks associated with our dependence on third parties for manufacturing activities; risks that clinical development activities may not be completed on time or at all, or may be delayed for regulatory, manufacturing, COVID-19 or other reasons, may not be successful or replicate previous clinical trial results, may fail to demonstrate that our product candidates are safe and effective, or may not be predictive of real-world results or of results in subsequent clinical trials; risks that the potential benefits of the agreements with our collaboration partners may never be realized; whether the survey findings represent the experiences of people living with PD; whether the Company can successfully encourage awareness that may help address the unmet needs of people living with PD; and other risks described in the Company's periodic reports filed with the Securities and Exchange Commission, including without limitation the Company's quarterly report on Form 10-Q for the quarter ended June 30, 2022. Neurocrine Biosciences disclaims any obligation to update the statements contained in this press release after the date hereof.



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