

## Unique patient-led and co-authored analysis of the experience of living with myasthenia gravis published in *Neurology and Therapy*

- *New analysis led by patients from across Europe and the United States provides first-hand insight into the lived experience of myasthenia gravis*
- *The analysis highlights five key themes that are central to the patient experience*
- *Patient advocates behind the paper call for greater understanding of myasthenia gravis and more open dialogue between patients and doctors*

**Brussels, Belgium and Atlanta, Ga. – 27 October 2021 07:00** – A new, patient-led research analysis published this week in the journal *Neurology and Therapy* reveals the lived experience of myasthenia gravis (MG) and calls for greater understanding of the reality of living with MG, through the eyes of the patient.

In a collaboration between people living with MG and UCB, a global biopharmaceutical company, 'The Lived Experience of Myasthenia Gravis: A Patient-led Analysis' is a unique, patient study to explore and assess the real-life impact of MG and current gaps in care. The qualitative research explored the significant physical, psychological, social and day-to-day experience of living with the rare autoimmune condition and identifies a need for improved dialogue between patients and clinicians. The study was led by the Patient Council – nine individuals living with MG who serve as patient advocates across Europe and the United States – and co-authored by two Patient Council members.

*"This patient analysis has unearthed the true reality of what it means to live with myasthenia gravis,"* said joint lead author Kelly Davio, MG patient expert, London, UK. *"Listening to individuals and exploring what their insights mean for the current care of patients is an essential project and our findings will help fill a significant number of knowledge gaps. Our research has clearly highlighted an urgent need for improved physician-patient communication and greater, more nuanced understanding of MG – not only the physical symptoms, but how the disease impacts patients' everyday lives."*

MG has annual incidence of 8 – 10 cases for every 1 million and can occur at any age and in any race.<sup>1,2</sup> As a chronic neuro-muscular condition where the body's immune system mistakenly targets the connections between nerves and muscles, patients can experience unpredictable, fluctuating symptoms such as fatigue, muscle weakness and difficulty breathing and swallowing.<sup>3-5</sup>

### Five key themes on the reality of living with MG<sup>6</sup>

Analysis of the qualitative patient research uncovered five key themes that are central to the patient experience:

1. **The lives of people with MG are dominated by unpredictable, fluctuating symptoms, with periods of worsening and remission**, causing uncertainty that makes planning challenging and creates feelings of vulnerability, which patients describe as being worse than the physical symptoms themselves
2. Consequently, **people with MG constantly have to adapt and accept trade-offs as part of their everyday life** – including in the critical areas of work, family planning and treatment
3. **Patients perceive a 'treatment inertia' in both themselves and their clinicians**, which results in them not always receiving the level of care they need
4. **People with MG can feel disconnected from their physicians** due to communication barriers and conflicting perspectives on the disease, treatment burden and treatment goals

5. **MG takes an emotional toll on patients**, with many experiencing feelings of anxiety, frustration, guilt, anger, loneliness and depression, driven by the burden of disease, social isolation, loss of control and lack of support

'Matthieu', a patient living with MG said: *"People don't really understand the everyday experience of myasthenia gravis. It can have a negative impact on almost all aspects of your work and family life, including basic functions of moving, eating, talking, and breathing. I hope this report will help drive a greater understanding amongst physicians and the general public, on the reality of living with this condition – not just in terms of physical symptoms, but also in how we have to constantly adapt our lives just to manage and the emotional impact this has."*

Kenza Seddik, UCB Patient Experience Lead & co-author added: *"While myasthenia gravis is rare, reported incidence rates are increasing, which is thought to be due to improved diagnostic techniques and an increased awareness of the disease. There is a growing wealth of published literature on myasthenia gravis, but few studies have explored the nuances of the patient experience. Through this analysis, we aim to give patients a voice so that we could gain a deeper understanding of the multifaceted lived experience of this condition. We hope that by sharing the findings from this study, we can help facilitate better-informed patient care and trigger more interest in listening to what patients say and putting their interests first."*

The development of 'The Lived Experience of Myasthenia Gravis: A Patient-led Analysis' manuscript was led by two patient advocates MG, Nancy Law from Colorado, USA and Kelly Davio from London, UK. The report is the result of detailed patient input and an exhaustive literature search, offering an unprecedented level of first-hand information for healthcare providers into the challenges facing people living with the condition. The study has been published posthumously following Nancy's death in September 2021 and her invaluable contribution to this paper and leadership of the MG patient advocacy community is hugely appreciated by all involved.

### **About myasthenia gravis**

MG is an unpredictable, chronic auto-immune condition in which auto-antibodies attack specific proteins at the neuro-muscular junction. This disrupts the way that nerves can communicate with muscles, resulting in muscle weakness and fatigue. Both men and women are impacted equally, and it can occur at any age and in any race. Myasthenia Gravis is a rare disease with an annual incidence of 8 – 10 cases for every 1 million<sup>1</sup>. Those living with MG can experience a variety of symptoms, including drooping eyelids and double vision as well as severe muscle weakness that can result in life threatening weakness of muscles of respiration.

### **About UCB in Rare Diseases**

At UCB, we don't just see patients or population sizes, we see people in need. Through decades of serving the neurology and immunology communities, we have improved lives with impactful medicines and by enhancing the social and emotional well-being of patients. As a continuation of our heritage, we are now expanding our efforts to tackle rare neurological and immunological diseases where current options offer little hope.

### **About UCB**

UCB, Brussels, Belgium ([www.ucb.com](http://www.ucb.com)) is a global biopharmaceutical company focused on the discovery and development of innovative medicines and solutions to transform the lives of people living with severe diseases of the immune system or of the central nervous system. With more than 7 600 people in approximately 40 countries, UCB generated revenue of € 5.3 billion in 2020. UCB is listed on Euronext Brussels (symbol: UCB). Follow us on Twitter: @UCB\_news

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<sup>1</sup> Gilhus N et al. Myasthenia Gravis. *N Engl J Med.* (2016)29;375(26):2570-2581. Doi: 10.1056/NEJMra1602678

<sup>2</sup> Carr, A.S., Cardwell, C.R., McCarron, P.O. et al. A systematic review of population based epidemiological studies in Myasthenia Gravis. *BMC Neurol.* 10, 46. (2010) 18;10:46. Doi: 10.1186/1471-2377-10-46.

<sup>3</sup> National Institute of Neurological Disorders and Stroke. Myasthenia gravis fact sheet. <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Myasthenia-Gravis-Fact-Sheet> (Last accessed: September 2021).

<sup>4</sup> Myasthenia Gravis Foundation of America. Myasthenia gravis quick facts. <https://myasthenia.org/What-is-MG/MG-Quick-Facts> (Last accessed: September 2021).

<sup>5</sup> Conquer Myasthenia Gravis. What is MG? <https://www.myastheniagravis.org/about-mg/what-is-mg/> (Last accessed: September 2021).

<sup>6</sup> Law, N., Davio, K., Blunck, M. et al. The Lived Experience of Myasthenia Gravis: A Patient-Led Analysis. *Neurol Ther* (2021). <https://doi.org/10.1007/s40120-021-00285-w>