

## **Patient Voice in Gout: Survey shows high unmet need and low expectations of treatment**

**Madrid, Spain, 12 June 2019** – A pan-European survey initiated by Grünenthal and presented at this year's annual European Congress of Rheumatology (EULAR 2019) in Madrid indicates that gout is being diagnosed late and is not controlled effectively or monitored regularly enough. Despite these significant gaps in the management of the disease, 8 out of 10 patients claim they are satisfied with their current treatment<sup>1</sup>.

"It is devastating to see that patients suffer in silence and do not seek better quality care. For us, this is a call to action to request better education of patients and their doctors about the best possible management of gout," says Victoria Romero Pazos, President of the Spanish Rheumatological League (LIRE) and President of the Agora Platform.

The survey was supported by 12 international and national patient organisations and included 1,100 gout patients from 14 European countries. It found a quarter of these patients were not diagnosed until they had suffered 4 or more flares, while over 70% had suffered a flare within the last year (a third of them had suffered more than three). Less than half were monitored for serum uric acid 2 or more times a year, only 58% received treatment to lower uric acid levels and 59% did not have regular follow-up appointments.

Patients reported that gout has a significant impact on their lives, for example by affecting their ability to walk (59%) or their mental health (46%). 10% of patients (or one of their family members) had lost a job or retired due to their gout. 34% of respondents said their pain was intense, severe or unbearable. "Feels like something eating your bone from the inside. Prevents normal physical activity and causes anxiety" was the description from one Irish patient<sup>2</sup>.

The survey indicates that there is a stigma surrounding the disease. Patients may be embarrassed to discuss their condition or flares with their doctor<sup>2</sup>. The respondents stated that, rather than rheumatologists, general practitioners were more often involved in the diagnosis of the disease (73% vs. 8%), the discussion of gout (68% vs. 15%), and the treatment of their last flare (59% vs. 11%).

Gout is the most common form of inflammatory arthritis that can develop in people who have high levels of uric acid in the blood (i.e. hyperuricemia). The acid can form needle-like crystals in a joint and cause sudden, severe episodes of pain, tenderness, redness, warmth and swelling. Gout is associated with multiple comorbidity and is potentially "curable" by reducing

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<sup>1</sup> DeMeulemeester M, Jansen T, Petersen G, et al. European patient voice in gout survey – subjective satisfaction in gout patients versus objective suboptimal gout care. EULAR 2019; Madrid: Abstract OP0157-HPR.

<sup>2</sup> Vieira A, Micallef S, Vella M, et al. Patient Voice in Gout – A European Patient Survey to Understand the Needs of People Living with Gout. EULAR 2019; Madrid: Abstract PARE 0014.

serum urate to normal levels using drugs that are currently available and by addressing modifiable risk factors for hyperuricemia. Gout affects up to 2.5% of people in Europe and its incidence and prevalence are rising<sup>3</sup>.

### **About the “Patient Voice in Gout” survey**

The project was initiated by Grünenthal in 2018 and was supported by 12 international and national patient organisations in Europe. The 15-minute online survey was developed with patient and clinical experts. There were 1,100 responses from patients with gout (who had suffered an average of 2.9 flares in the past 12 months). The patients were based in Austria, Belgium, France, Denmark, Germany, Italy, Ireland, Malta, Netherlands, Norway, Portugal, Spain, Sweden, and Switzerland.

### **About Grünenthal**

Grünenthal is a global leader in pain management and related diseases. As a science-based, privately-owned pharmaceutical company, we have a long track record of bringing innovative treatments and state-of-the-art technologies to patients worldwide. Our purpose is to change lives for the better – and innovation is our passion. We are focusing all of our activities and efforts on working towards our vision of a world free of pain.

Grünenthal is headquartered in Aachen, Germany, and has affiliates in 30 countries across Europe, Latin America and the US. Our products are available in more than 100 countries. In 2018, Grünenthal employed around 4,900 people and achieved sales of € 1.3 bn.

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<sup>3</sup> <https://www.eular.org/myUploadData/files/RheumaMap.pdf>