

# Living with hypoparathyroidism: the first worldwide survey of daily life for patients and carers

The prevalence of hypoparathyroidism, also known as hypopara, is estimated to be **24-37 per 100,000 person-years**.<sup>1</sup> The rare and lifelong endocrine disorder is often caused by damage to or removal of the parathyroid glands following thyroid surgery.<sup>2,3</sup> **398 patients** and **207 carers** from **13 countries** share their lived experiences in a Burden of Illness survey, conducted by a group of international experts and patient organizations and supported by Takeda<sup>4</sup>, to add to our knowledge and greater understanding of this disease.

## 1. People with chronic hypopara can experience a range of physical and cognitive symptoms that can be severe and debilitating<sup>4</sup>



## 2. Patients experience symptoms despite being on conventional treatment, reporting an empathy gap with their physicians<sup>4</sup>



## 3. When not properly controlled, chronic hypopara can affect employment and productivity of both the patient and carer<sup>4</sup>



## 4. Following a diagnosis of hypopara, personal relationships for patients and carers are put under strain<sup>4</sup>



The immense impact on quality of life resulting from hypopara symptoms and the attendant burden on their carers cannot be underestimated. Sharing research of this kind reveals new insights into this rare condition, providing invaluable information to the community and to physicians, and highlights the importance of also focussing on the quality of life of patients, especially those who are not adequately controlled.

Takeda is committed to making a meaningful difference for people with rare conditions such as chronic hypoparathyroidism – to find more information about the rare condition, visit: [www.hypoparaanswers.eu](http://www.hypoparaanswers.eu)

### References:

1. Abate et al. Review of Hypoparathyroidism. Front Endocrinol. January 2017; 7: 172
2. Bollerslev J, Rejnmark L, Marcocci C, et al. European Society of Endocrinology clinical guideline: treatment of chronic hypoparathyroidism in adults. Eur J Endocrinol. 2015;173:G1-G120
3. Brandi ML, Bilezikian JP, Shoback D, et al. Management of hypoparathyroidism: summary statement and guidelines. J Clin Endocrinol Metab. 2016;101:2273-2283.
4. Siggekow H, Clarke BL, Germak J, et al. Burden of illness in not adequately controlled chronic hypoparathyroidism: Findings from a 13-country patient and caregiver survey. Clin Endocrinol (Oxf). 2020;92:159-168. <https://doi.org/10.1111/cen.14128>