Recordati: Roundtable on the under-treatment of patients with endogenous Cushing's syndrome

Cushing's syndrome: Germany brings up the rear



The roundtable participants – from left to right PD Dr Heide Hoffmann and Dr Andreas Böhme (both from the Network for Pituitary and Adrenal Disorders e. V.), a person living with Cushing's syndrome, moderated by Dr Dirk Maessen (Recordati Rare Diseases Germany GmbH), Prof. Dr Martin Fassnacht (University Hospital of Würzburg), Dr Linus Haberbosch (Charité Berlin), Nora Seitz, Member of the Bundestag (rapporteur for rare diseases for the CDU/CSU parliamentary group).

At the health policy roundtable organised by Recordati Rare Diseases in Berlin in June 2026, Nora Seitz, Member of the Bundestag and rapporteur for the CDU/CSU parliamentary group on rare diseases, Prof. Dr Martin Fassnacht, University Hospital of Würzburg, President-elect of the German Society for Endocrinology (DGE), Dr Linus Haberbosch, Charité Berlin, health policy spokesperson for the DGE, and patient representatives PD Dr Heide Hoffmann and Dr Andreas Böhme, both from the Network for Pituitary and Adrenal Disorders e.V., and a person living with Cushing's syndrome, discussed structural gaps in care for rare endocrinological conditions. The debate highlighted the close links between the shortage of specialists, late diagnoses and current reform plans.

>> Endogenous Cushing's syndrome is caused by a pathological excess of the stress hormone cortisol, usually triggered by a benign tumour of the pituitary gland or adrenal gland. Because the symptoms are varied and non-specific, the condition is often not recognised until many years later. In one patient's case, it took around nine years to reach a diagnosis. Her symptoms – uncontrollable high blood pressure, headaches, pre-diabetes, depression, muscle weakness and weight gain with the typical 'moon face' – could not be explained by specialists until an ultrasound scan carried out by a cardiologist revealed a tumour on her adrenal gland. "I'm from Mecklenburg-Western Pomerania – I don't know a single practising endocrinologist there," she stated for the record.

With around 0.81 endocrinologists per 100,000 inhabitants, Germany has the lowest density of specialists in Europe (as of 2024). According to Haberbosch, the figure should be around 2.7. "We're at the bottom of the table across Europe when it comes to the density of endocrinologists," said the DGE's health policy spokesperson. Nationwide, there is a shortfall of around 1,100 endocrinologists. The result: Cushing's patients wait 2.8 years for their diagnosis worldwide, and 4.8 years in Germany. Fassnacht pointed to the more than twelve million people with hormonal disorders: For common conditions such as diabetes and obesity, care from a GP is often sufficient, but complex cases must be referred to specialists, which is hardly realistic given the current density of specialists.

Haberbosch and Fassnacht take a critical view of the Hospital Reform Adaptation Act: in future, service groups could be staffed by a specialist in internal medicine with a one-year additional qualification in diabetology, rather than by a specialist in endocrinology and diabetology who has undergone six years of training. A doctor with a supplementary qualification in diabetes would not be professionally qualified to treat Cushing's patients, warned Fastnacht, describing this as "false labelling". He argues that it would be better to have a few hospitals that could actually provide the care than many that merely bear the designation in name only. Haberbosch, however, also sees the reform as a means of firmly establishing a specialist in endocrinology within the service groups. Similarly, the DGE president-elect made it clear that it all starts with the next generation: "If students don't learn about rare diseases whilst at university, they won't go on to specialise in that field either."

There was broad consensus on the importance of coordinated care. Rare diseases require close collaboration between specialist disciplines, specialised centres and patient organisations. "We in Germany must significantly improve our diagnostic capabilities and refer patients to the right places more quickly," emphasised Seitz. In view of the tight financial situation, she called for action at the state level. "I can only recommend that everyone makes their voice heard and repeatedly raises this issue with the relevant decision-makers," explained the CDU politician.

Patients are particularly well-placed to convey this message credibly. This is where the Network for Pituitary and Adrenal Disorders e. V.[1] comes in: over 30 regional groups, around 4,000 members, and growth of almost 20 per cent by 2026. The network is so important for individuals because those affected are ultimately left to fend for themselves. Patient representative Böhme criticised in particular the patchy discharge management, which leaves many patients on their own after their hospital stay. Self-help groups need to support them and establish links with university hospitals.

These challenges have been known for many years. It will be crucial to continue the dialogue and to further develop training, diagnostics and care structures in concrete terms. << by: Mariann Stegmaier M.Sc. **1:** https://www.glandula-online.de/