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**Cushing's Syndrome:
Normalization of Cortisol is Just
the Beginning**



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Introduction

Cushing's Syndrome is caused by elevated levels of cortisol and is characterized by dozens of non-specific physical, metabolic, and neuropsychological symptoms. The extent of damage a patient will face is directly related to time to diagnosis, experience of the doctors and surgeon, and the support and education they receive after surgery. The spectrum of long-term needs faced by patients who have been exposed to prolonged elevated cortisol are not well represented in the literature and not well understood by most doctors.

Method

In 2023, a committee of patient advocates built a quality of life survey with over 150 questions using examples from two previous patient-created studies. This survey was translated into Spanish and French, then shared amongst multiple global support communities. SurveyMonkey was used for layout and response collection.

Results

The survey received 438 responses from 38 countries. Though the majority of respondents were from the United States, the unprecedented collaborative efforts of international patient organizations was reflected in the volume of responses and added depth to the data. Cushing's is overwhelming – Over 90% of respondents said they were negatively impacted by the complexity of symptoms and that it is almost impossible to fully understand the diagnosis in the beginning.

Delay in diagnosis equates to worse long-term prognosis – It took more than 10 years for a full quarter of respondents to get an accurate diagnosis.

Mental health support is vital – It was nearly unanimous that mental health support should be part of a patient treatment package (99.3%) and that therapy can be helpful even when a patient has good coping skills (95.7%); a need to process trauma after Cushing's was expressed by 92% of participants.

Peer support can be priceless – 98% agree that it is beneficial to share experiences with other patients, and 94% said that a "peer sister" or "peer brother" to guide a patient along the way would be helpful.

The devastating reality – Almost three quarters of patients reported that grief has been constantly present throughout the journey and they were not prepared for what life was like after surgery, and concern is nearly unanimous about life-shortening cardiovascular damage and changes to the brain.

Conclusion

For a rare disease like Cushing's, it is imperative to partner with an advocacy group that can help provide crucial missing data that paints a bigger picture of the patient experience and ultimately leads to faster and better treatment.

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