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NO CONFLICTS OF INTEREST TO DISCLOSE

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INTRODUCTION

Cushing's Syndrome damages physical, neuropsychological, and mental health. Some clinical and surgical statistics have improved over time, but patients persistently report delays to diagnosis, confusion about treatments, and the feeling of being "dropped" once cortisol is normalized. Patients also report that long-term health challenges are often treated without consideration of the role hypercortisolism played in their creation. Inappropriate treatment, or no treatment at all, is far too common.

HYPOTHESIS

Patients around the globe support each other and share best practices related to elements of the journey that are misunderstood, dismissed, and under-treated in the clinical setting. Patient-created data can be professionally translated and made available to supplement clinical data via patient registry. The raw, honest human experience of this disease is vital for clinicians and researchers to understand and incorporate into their work for better short- and long-term care and results.

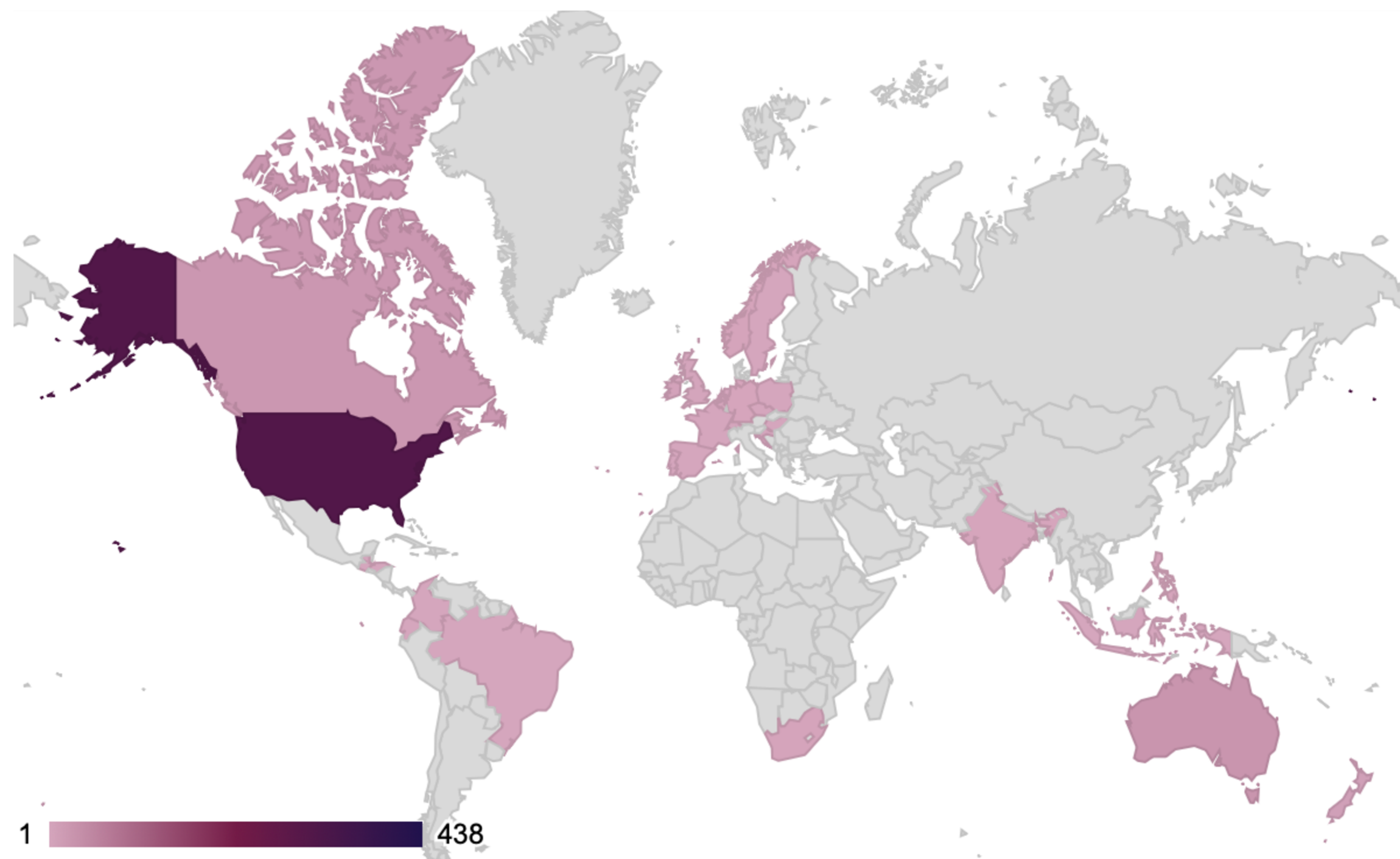
METHODOLOGY

CSRFB convened an international patient committee to review design and content of two previous Quality of Life surveys and add new content to create more than 150 questions for this one. SurveyMonkey was used for layout and response collection. Spanish and French translations were done with DeepL and verified by native speakers. The survey was promoted within global patient advocacy organizations and on social media; it received 438 responses from 38 countries.

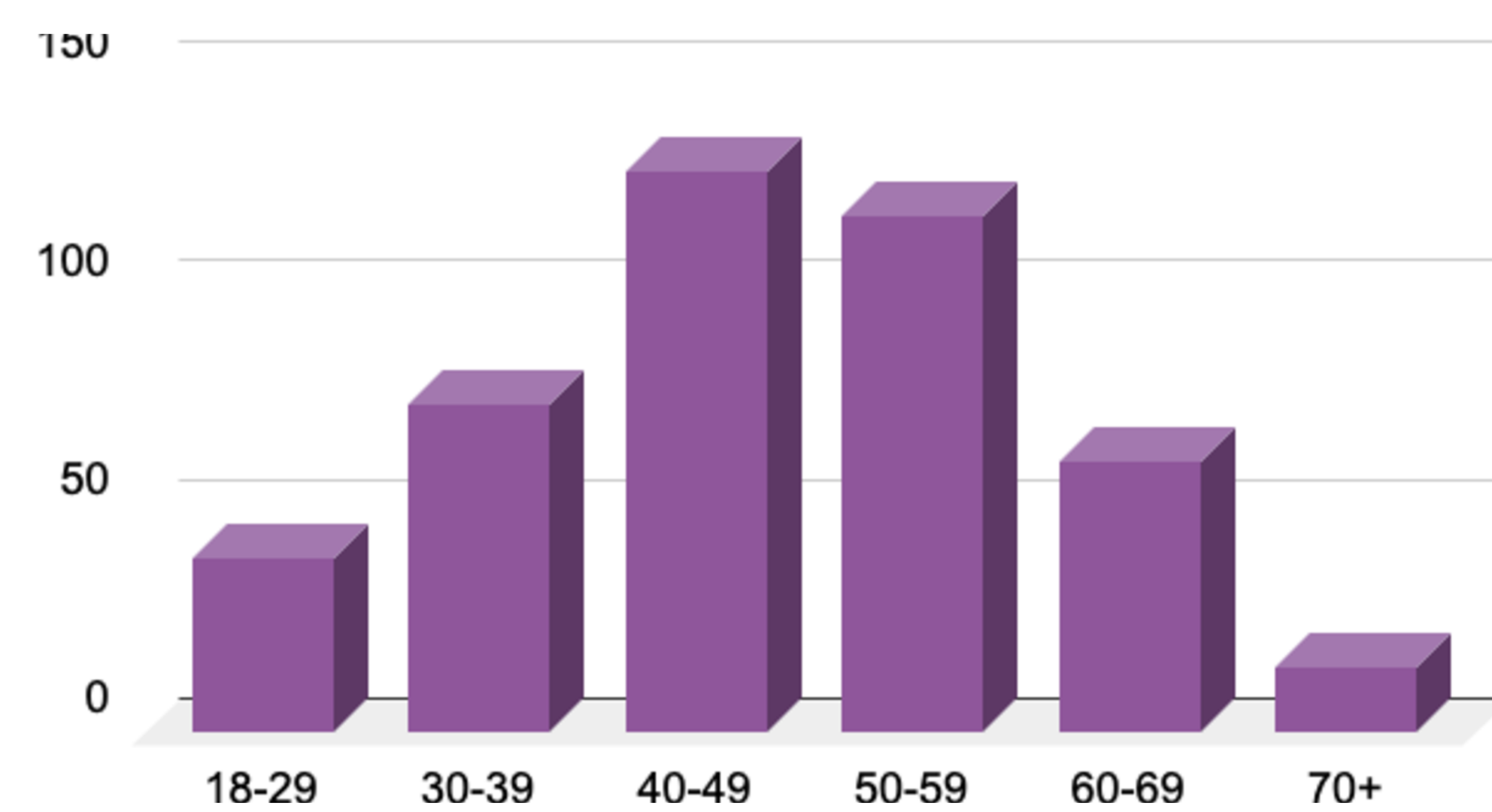
DEMOGRAPHICS

Global Representation

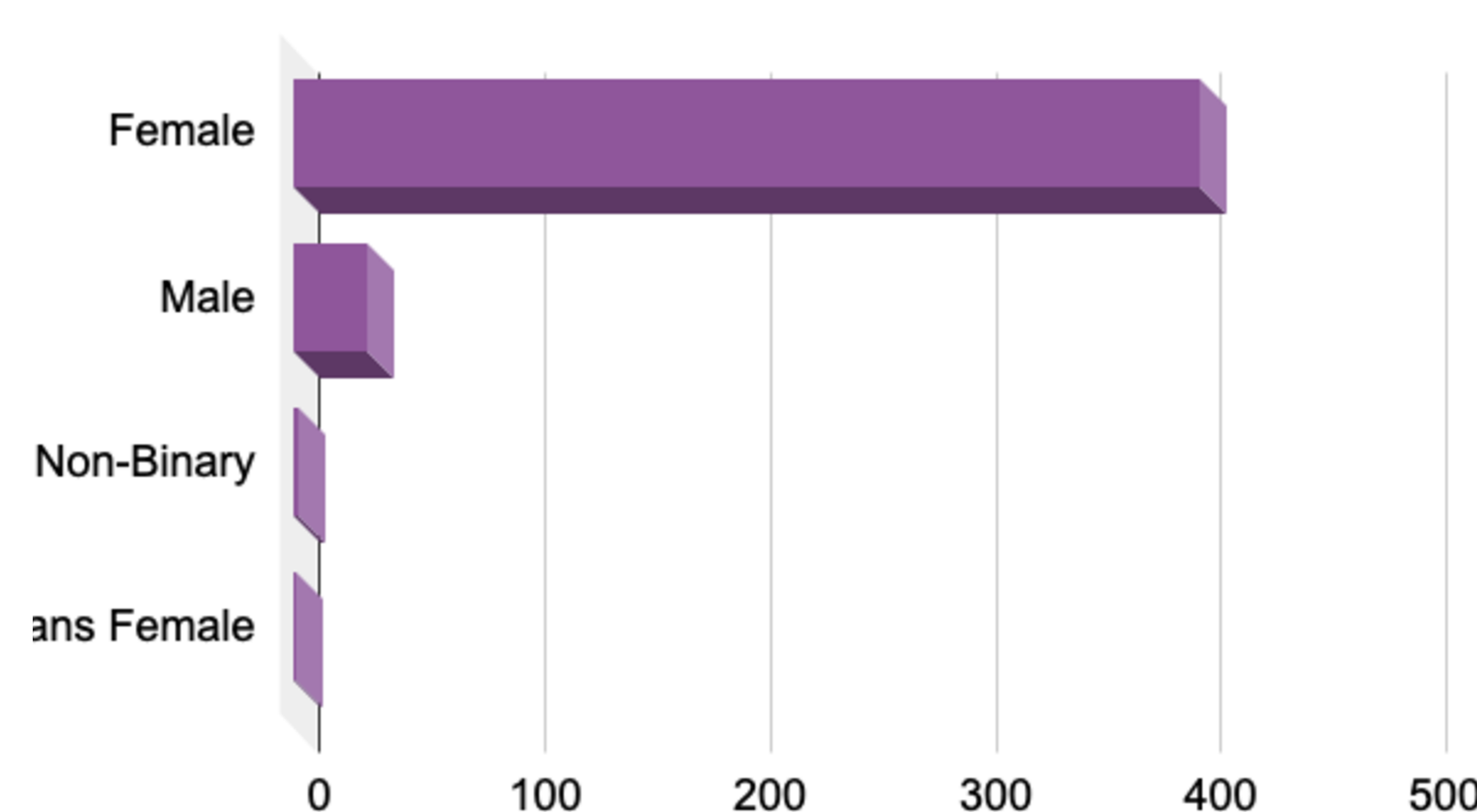
(United States, Canada, Europe, Oceania, Asia, Africa, South America)



Respondents by Age



Respondents by Gender



RESULTS

Though a majority of respondents are in the US, the unprecedented collaborative effort of international patient organizations was reflected in the volume of responses.

Imagine....over a period of several years, medical mysteries enter your life, or that of a loved one:

One day your favorite jeans no longer fit, so you dig out those pants with the elastic waist and swear to eat more vegetables.

Several months later, you suddenly break out in acne on your face and neck, some of it cystic, but it fades just before you make an appointment.

You begin waking up at 3:15am, and at first you make the best of it, but your heart pounds so loudly, and it's making you anxious.

Your blood pressure is high so you go on a medication. You've gained 12lbs since your last appointment, so they suggest the Mediterranean Diet.

Later that year, your spouse starts staying late after work, and it's kind of a relief because all you seem to do is fight about how the house is messy, you're angry all the time, and you're always asleep when they get home. You start therapy, and an antidepressant. Three months later you feel worse than before and you're heavier now too. You're told that medication can cause weight gain, so you switch to another.

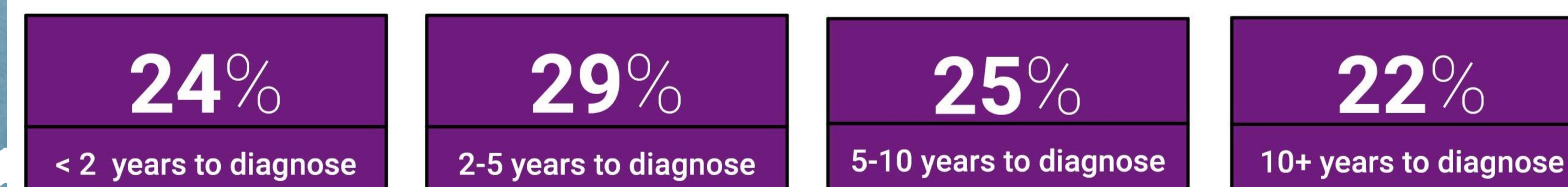
You get a second blood pressure med next time you visit your PCP because now you've got edema in your lower legs. You're embarrassed to show her because you've got bruises and scabs on your calves, and you've only got one pair of shoes left that fits. You've gained another 30lbs. No wonder your libido is shot - who would want you when you look like this? You're offered the get-thin-quick drug everyone's taking these days.

A friend who's just started on estrogen is now a hormone expert and thinks you have PCOS, but a visit to the gynecologist rules it out. She sympathizes with your irregular periods and lost libido and gently tells you that losing a little weight and seeing a therapist might be helpful.

WHEN DO YOU HAVE ENOUGH, AND ACKNOWLEDGE THAT THERE'S SOMETHING BIGGER GOING ON? THEN, HOW LONG DOES IT TAKE FOR YOU TO CONVINCE YOUR DOCTORS TO HELP YOU DIG DEEPER?

THIS IS A GLOBAL PROBLEM, AND IT IS NOT ACCEPTABLE.

IT TOOK MORE THAN 5 YEARS FOR HALF OF THESE PATIENTS TO GET A CORRECT DIAGNOSIS.



BY THE NUMBERS

100% We believe it is important to educate primary care providers about this condition.

98% This is a disease where it seems that most patients must get very sick before it can be diagnosed and treated.

96% We want to know long-term health data (20+ years), even if it might be scary.

92% "I would like to have access to a discussion group that is only open to verified patients so I know that I am talking to people who actually have or had Cushing's."

91% Visits to other specialists like pulmonologists and cardiologists should be part of the standard of care.

91% "I previously thrived in my career but now either struggle to keep up, have had to change jobs, or had to quit working altogether."

88% Cushing's has changed expectations and needs in our closest relationships.

80% We experienced fat shaming or bias in our quest for diagnosis.

73% We believe that all the various names for high cortisol lead to misinterpretation, self-diagnosis, and confusion.

70% We have experienced humiliation or rejection from people we know while in active Cushing's.

65% Our non-specialist doctors do or did not seem to understand how to interpret cortisol lab results.

51% "I have had suicidal thoughts."

20% "My marriage / long-term relationship did not survive Cushing's."

CONCLUSION

Cushing's symptoms are non-specific, and most of them appear, at first, as common metabolic problems. Until ALL doctors are aware of the damage of hypercortisolism, our non-endocrine physicians will continue to treat individual symptoms without addressing their root cause. It is more difficult than ever to get an appointment with a specialist, and most require confirmatory tests before accepting a patient for a full Cushing's workup. It is critical that we do something DIFFERENT: more effective education, clearer instructions for initial workups by non-specialists, and a paradigm shift on the value of pre-test suspicion and "rare bias" for a disease that can take many forms and is marked by dysregulation of a well-known hormone are a few places to start.

Partnering with a patient advocacy organization provides missing pieces of the puzzle, but also expands reach. We understand that there is only so much you can do. Let us do more with you, on behalf of all patients: the US Cushing's Patient Registry launches 2025.

REFERENCES

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