



QUALITY OF LIFE

A GLOBAL, COMPREHENSIVE SURVEY ANALYSIS OF CUSHING'S DISEASE PATIENTS

PRESENTED BY: CUSHING'S SUPPORT & RESEARCH FOUNDATION

WHO IS CUSHING'S SUPPORT & RESEARCH FOUNDATION?

PATIENT ADVOCACY, SUPPORT & EDUCATION

- Monthly support sessions
- Patient Registry, other patient-created QoL studies
- Patient education days
- Patient webinars and conferences
- Newsletter

AWARENESS TO PHYSICIANS & RESEARCHERS

- Advocate for clinical studies
- Medical Advisory Board
- Awareness to specialties beyond endocrinology (ex. Gynecology, Bariatrics, Somnology)
- Collaboration on projects and studies
- Providing the "missing link" - patient QoL data to complement clinical data

GLOBAL RESOURCE

- Physician directory
- Serve as a connector for patients globally
- All material can be used by others, translated
- Patient Advisory Committee/Ambassadors
- Support for WAPO and its organizations
- Global element to upcoming registry

CUSHING'S DISEASE & SYNDROME

Cortisol is essential to many of the body's systems and functions, but when it malfunctions, it can be life threatening if not treated properly.

The longer the patient has active Cushing's, the more outlying conditions the patient needs to have treated.

CSRF created a 'Quality of Life' survey that was shared globally with the support of other Foundations and groups as well as social media. The insights gained by the results will help patients, physicians and researchers work together for a better life.





QUALITY OF LIFE SURVEY

PROBLEM STATEMENT AND TARGET AUDIENCE

PROBLEM STATEMENT

The experience of living with Cushing's Disease presents a multifaceted challenge: **patients often feel isolated and uninformed about the condition**, while physicians are not armed with comprehensive information for holistic diagnosis and treatment.

Moreover, both patients and healthcare providers have limited understanding of the long-term repercussions of Cushing's Disease after treatment.

TARGET AUDIENCE

Diagnosed with Cushing's Disease or Syndrome by a medical professional

Ages 18 years and older

GOALS OF A QUALITY OF LIFE STUDY

1 Educational

Collective effort aimed at promoting better understanding, better care and improved outcomes for all patients.

2 Actionable

Global Advocacy groups and all stakeholders, including caregivers, have a role in changing the story. *Partnership and funding for awareness, support and events around the world will result from this survey analysis.*

3 Measurable

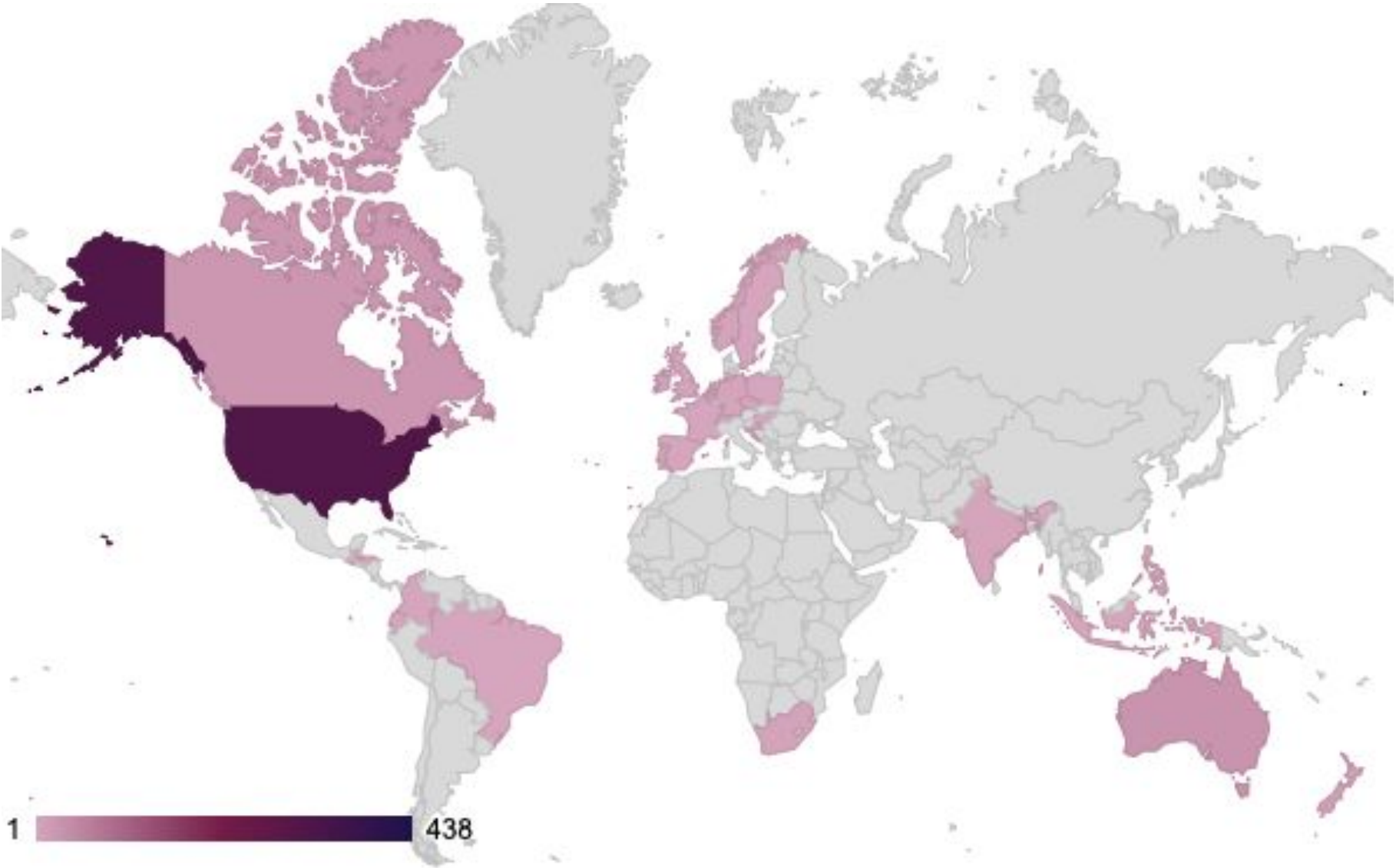
We want to know how patient peers compare across countries and see where improvements can be made through incorporating best practices.



QUALITY OF LIFE DATA

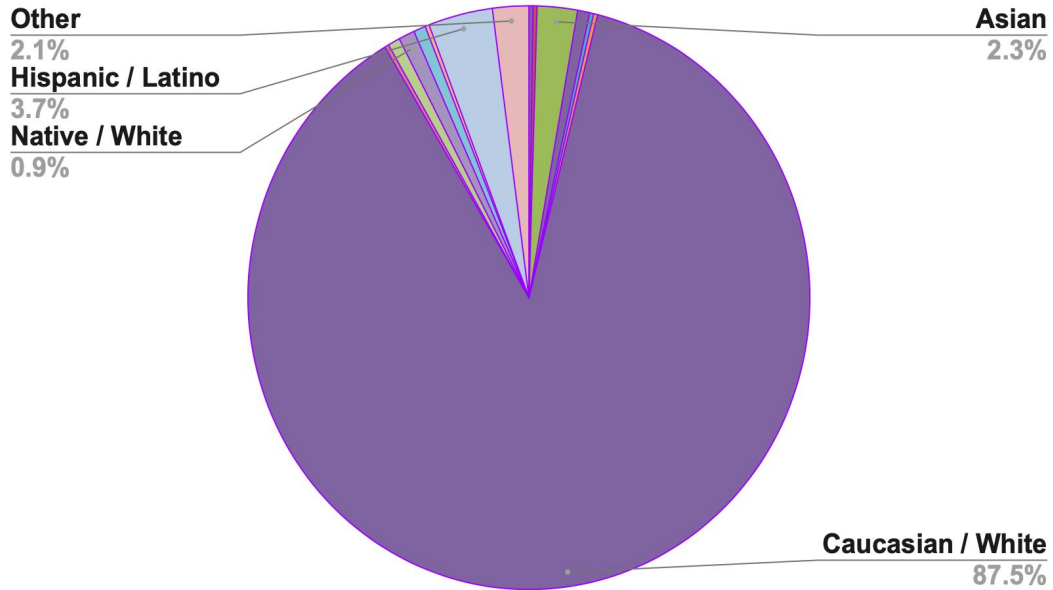
BY THE NUMBERS

- 438 Patients
- 31 Countries
- 6 Continents



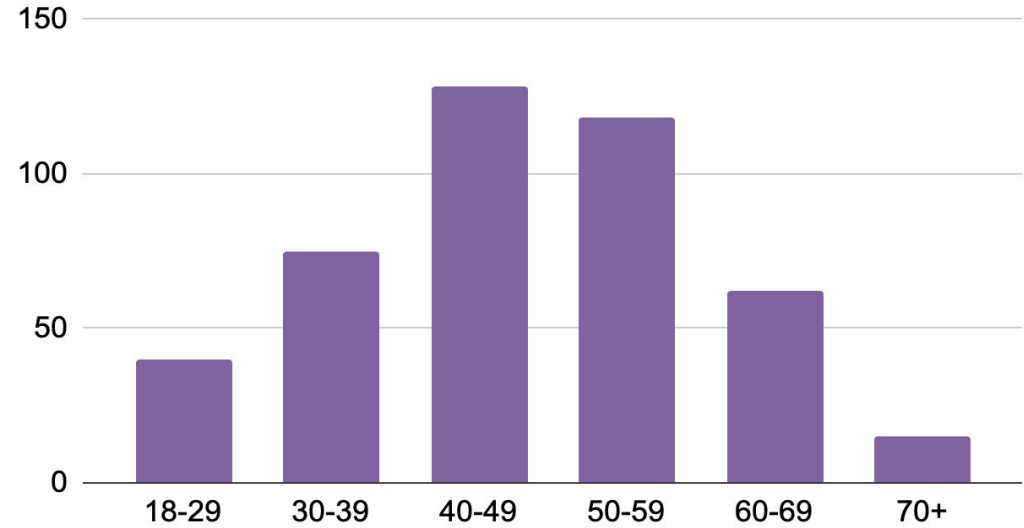
DEMOGRAPHICS

How would you best describe your race?

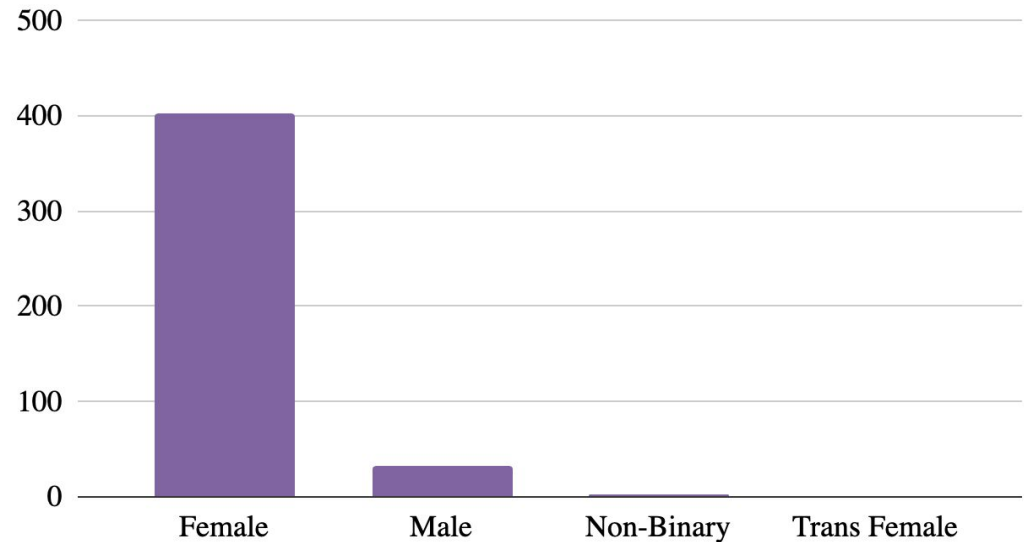


Other races represented:
Hawaiian/Pacific Islanders, Indigenous, African American and mixed.

Respondents by Age



Respondents by Gender



DIAGNOSIS

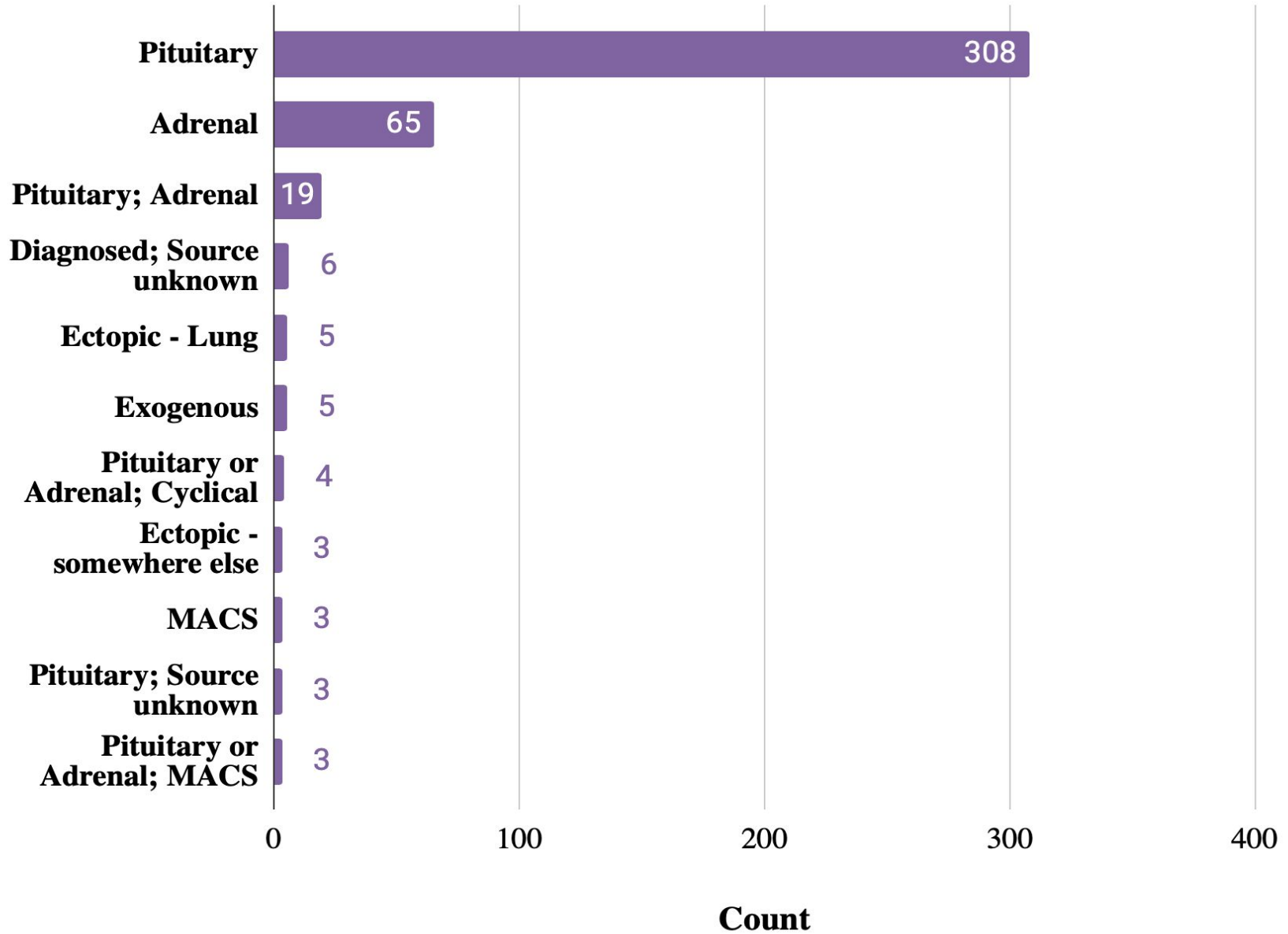
24%
 < 2 years to diagnose

29%
 2-5 years to diagnose

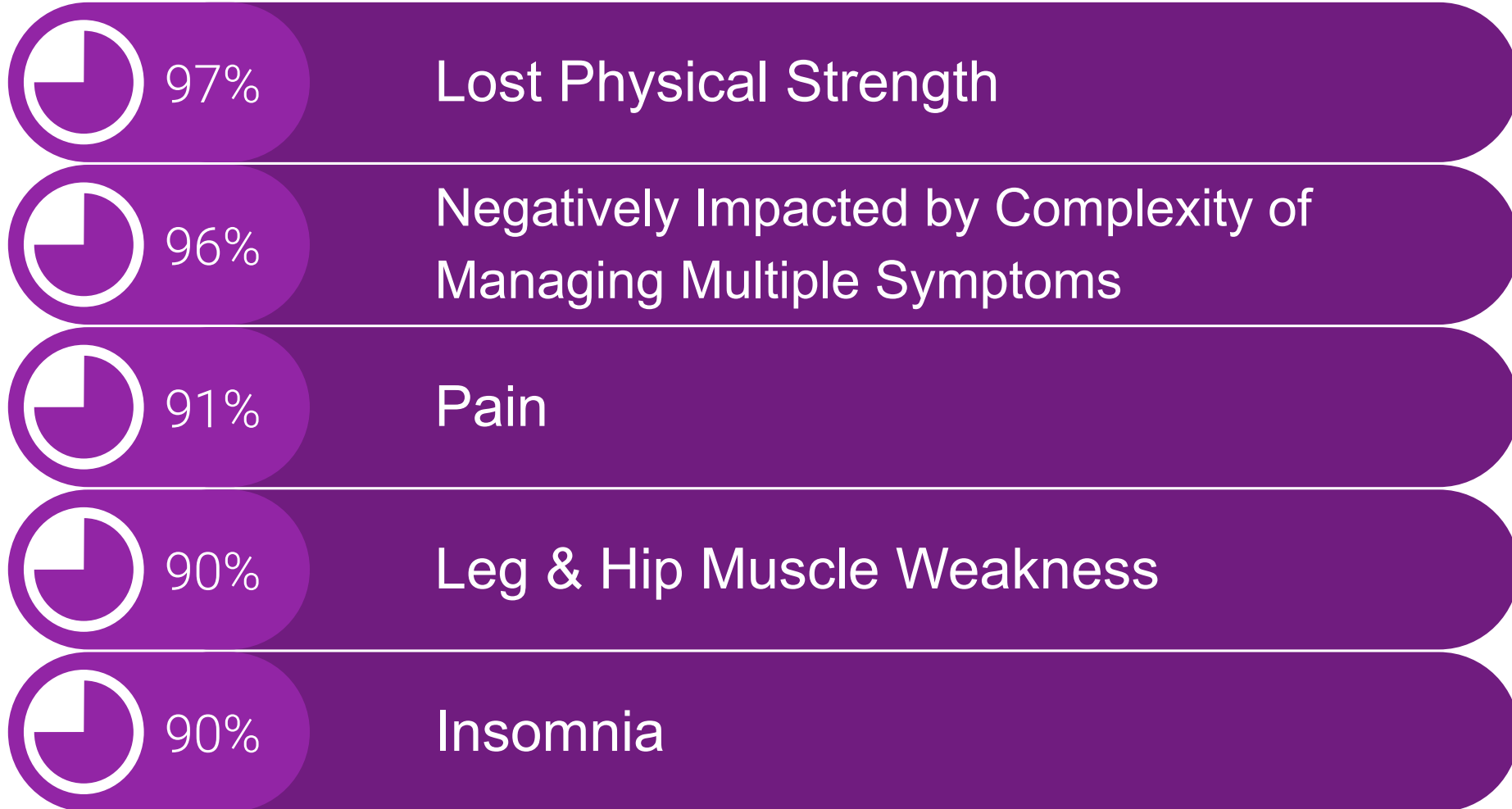
25%
 5-10 years to diagnose

22%
 10+ years to diagnose

What kind of Cushing's do / did you have?



SOME SYMPTOMS EXPERIENCED BY AT LEAST 9 OUT OF 10 CUSHING'S PATIENTS



PHYSICAL APPEARANCE

29%

I do not or did not have the classic Cushing's appearance and I feel like that delayed my diagnosis.

RELATIONSHIPS

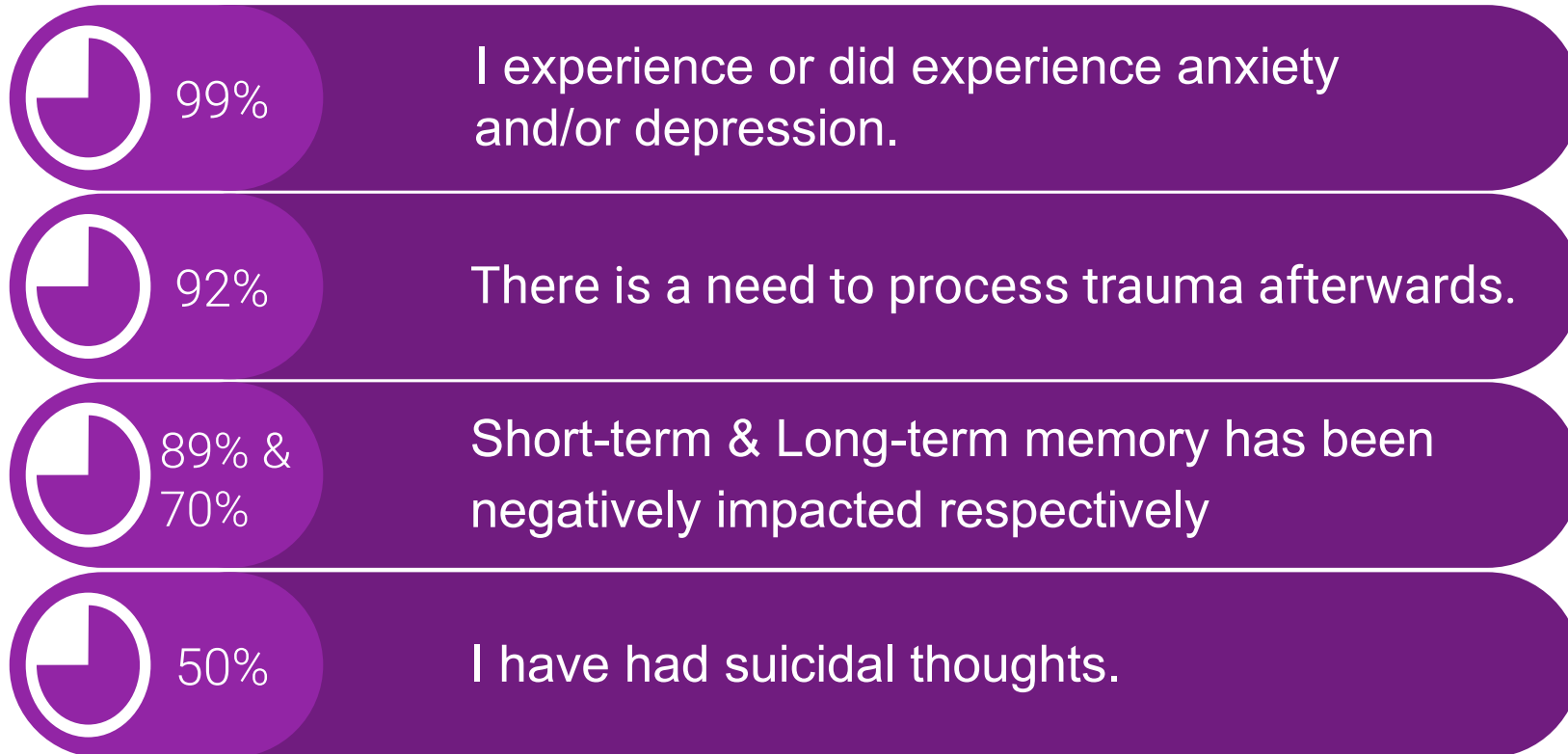
50%

I am or was negatively impacted by a family that does not understand or has lost patience with a treatment process that has been going on for a long time.

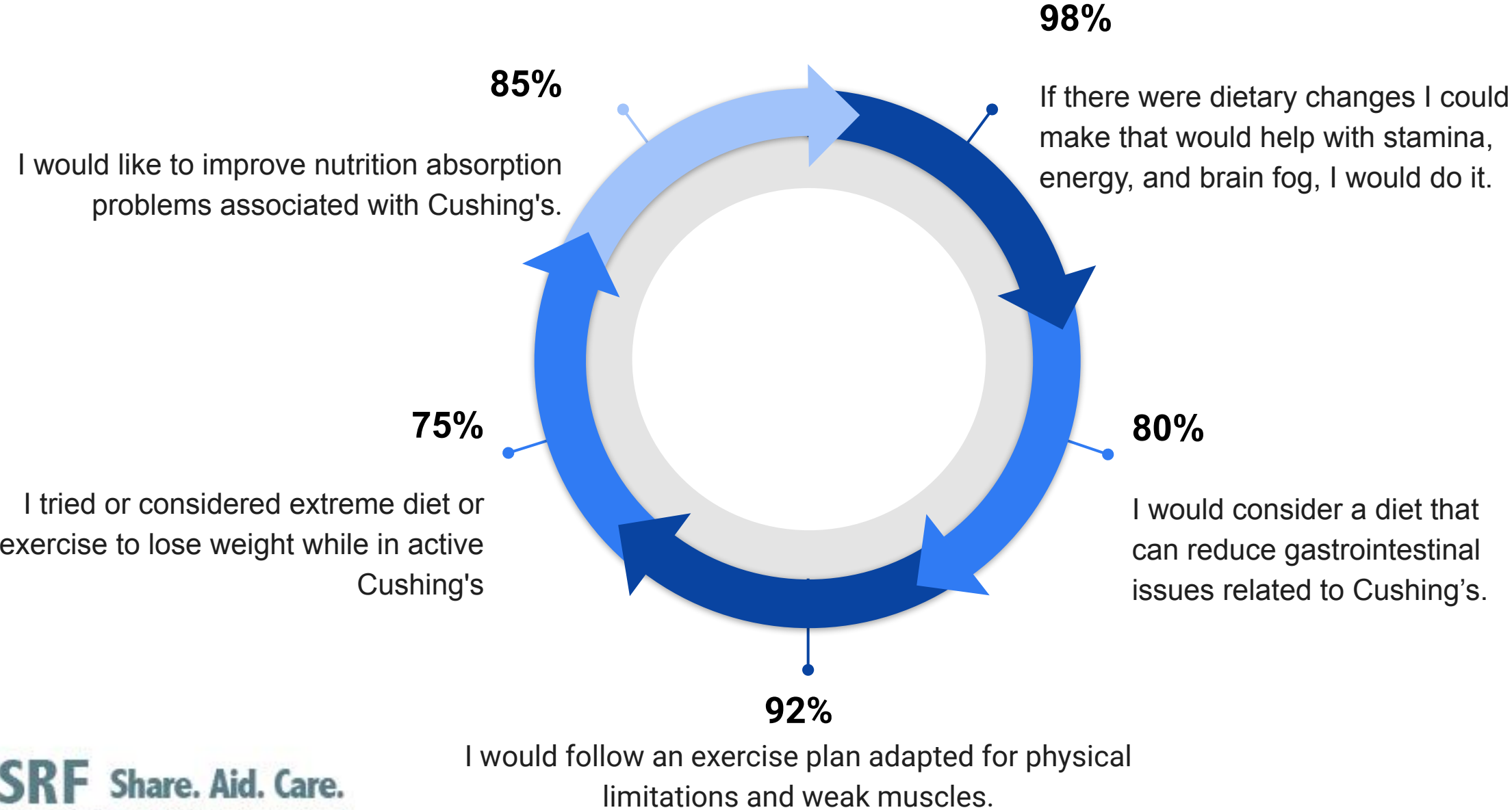
20%

My marriage or long-term relationship did not survive Cushing's.

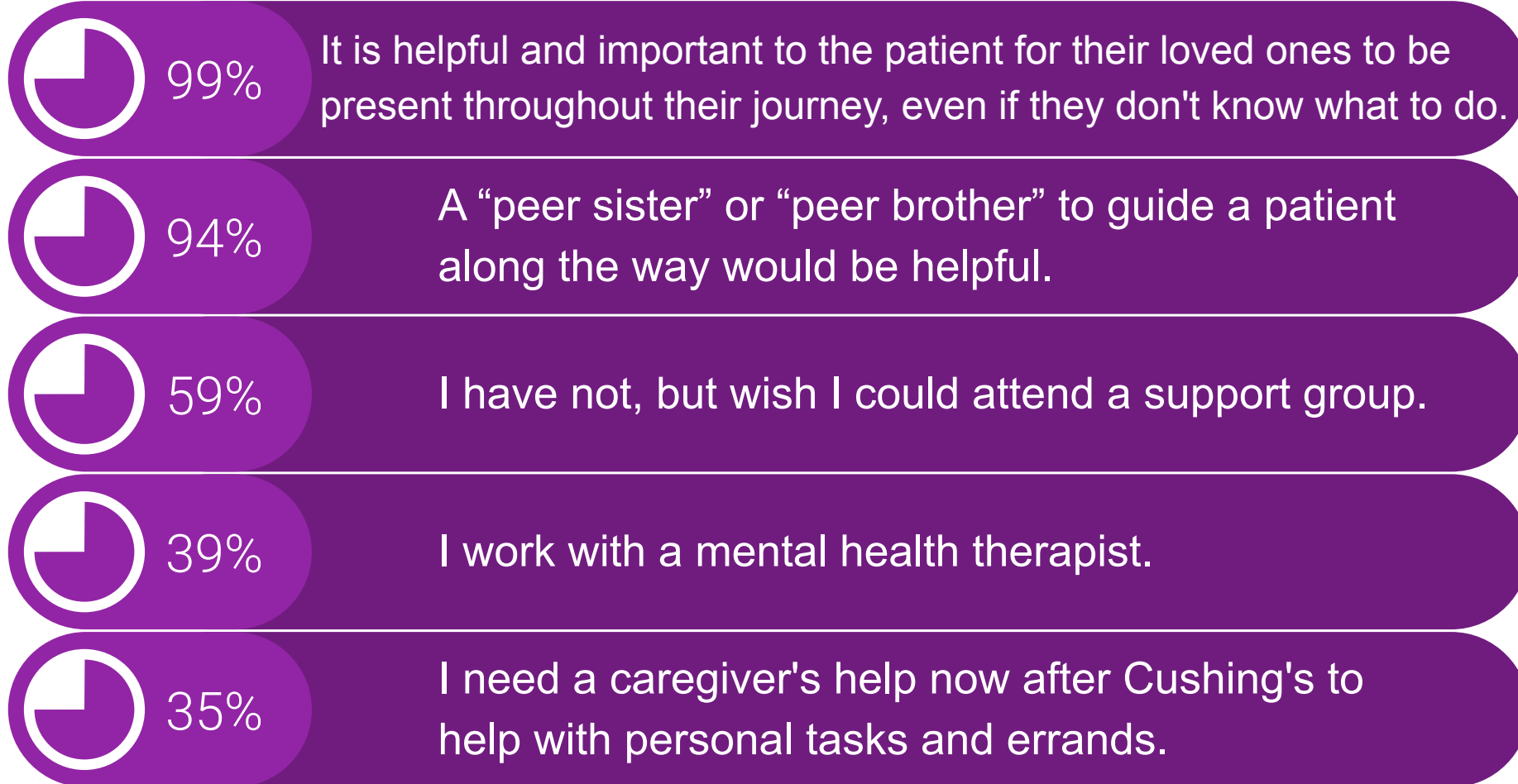
MENTAL HEALTH & MEMORY



DIET, NUTRITION & EXERCISE



SUPPORT NEEDS OFTEN INCREASE



CAREER DISRUPTION

59%

“I previously thrived in my career but now either struggle to keep up or have had to change jobs.”

31%

“I had to quit working permanently because of Cushing's.”

WHAT MY COWORKERS SEE
WHEN THEY LOOK OVER AT MY DESK



POST-SURGERY / ADRENAL INSUFFICIENCY

91%

There is a perception by most people that everything does or should go back to normal after surgery.

87%

You might need to prepare yourself to take much longer than 6 weeks, or even 6 months after surgery to return to work or normal activity.

61%

I wish I had been told before surgery about hydrocortisone tapering and what to expect.

57%

I have learned the majority of what I know about how to manage adrenal insufficiency from other patients instead of my doctor.

58%

All of my pituitary hormones have been tested to see if I need to supplement anything.

COPING & LONG-TERM CONSIDERATIONS

95%

There are so many negative things happening with Cushing's that it can be difficult to determine what is related and what is not.

96%

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

88%

I am concerned about negative impact from Cushing's on white and grey matter in the brain.

86%

I wonder if the roller coaster ever subsides – I feel like I'm ok some days but barely able to function on others.

95%

Healing is a slow process and does not only include normalization of cortisol.

90%

I feel or have felt that my health problems are all-consuming.

15%

After surgery, I have recovered back to pretty much my "old normal".

OBSERVATIONS

“I believe it is important to educate primary care providers, gynecologists and obesity doctors about this condition.”

↪ 100% respondents said Yes/Agree

“I am interested in learning more about pumps, patches, test kits, and other devices in the pipeline.”

↪ 77% said Yes/Agree

“I think visits to other specialists like pulmonologists and cardiologists should be part of the standard of care.”

↪ 91% said Yes/Agree

“Just because my blood test results fall in normal ranges, that does not mean my symptoms are gone or that I am ok.”

↪ 94% said Yes/Agree

“The classic Cushing's image is harmful because not every patient has stretch marks, a hump, or extreme weight gain.”

↪ 70% said Yes/Agree



PATIENT QUOTES

I wish doctors really could understand that surgery does not fix the damage of high cortisol for long periods of time. It takes years.

More Gyno's need to be aware of the impact of Cushing's before it's even diagnosed because I went years without a period and no Dr seemed to be concerned until now it's a problem with cancer.

The worst disease because no one understands. People hear cancer and they have an idea of what it means.

I had 2 weight-loss surgeries and a horrible open thoracic fundoplication one year before diagnosis.

If we have an at home glucose monitoring system, why is it so hard to do an at home cortisol monitoring system? It's a nightmare guessing if my levels are high, low or in range.

I am crushed of my dreams. Lost lots of friends. They could not understand me. Still don't.

Thank you for this survey. Just by you acknowledging these challenges and me being able to freely answer these questions has been so helpful....I don't really talk about it with many people.

I feel you have forgotten how Cushing's impacts the mental health. I was manic as undiagnosed, and did so many crazy things that have impacted my loved ones.

Cushing's is a monster that lives inside you. It's a battle to live with it, and then without it.

Even though I am no longer a Cushie, my health never went back to "normal".





WHAT'S NEXT?

TAKE ACTION

CUSHING'S SUPPORT & RESEARCH FOUNDATION

- **Further analyze the data** to identify trends and other important elements; note lessons learned.
- **Engage researchers** and/or members of our Medical Advisory Board to review the data and our initial summaries with commentary.
- **Publish the results** to medical professionals and Cushing's patient communities, distribute widely!
- Create a presentation and poster for 2024 **international conferences**.
- **Build an energized team to bring our patient registry to life.**

TAKE ACTION

MEDICAL COMMUNITY

- Help design and agree to **distribute patient materials** that will support them beyond the clinical setting.
- Start a **professional conversation about the role cortisol testing can play in a broader scope**, when certain symptoms are present even if it is not overt and florid endogenous disease.
- Establish a pattern of **connecting patients to CSRF or another local patient support organization** at the first appointment.
- Spread knowledge and understanding that **patients will need support throughout their treatment and years of recovery.**
- Share feedback and ideas for the patient registry, and **work with CSRF** to determine verification methods and how to recruit patients in the clinical setting.

TAKE ACTION

PATIENTS

- Join a support call**, recognizing others in their countries.
- Join the Patient Advisory Committee.**
- Join the **patient registry!**
- Become an ambassador** for new patients seeking support in your area, especially minorities.
- Be mindful of social media misinformation** and promote patient support efforts and awareness on your personal platforms.
- Share good, factful resources** with doctors, family, friends and others.



THANK YOU!

CUSHING'S SUPPORT & RESEARCH FOUNDATION ALONG WITH SUPPORTING ORGANIZATIONS



**SOCIAL MEDIA
GROUPS**

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