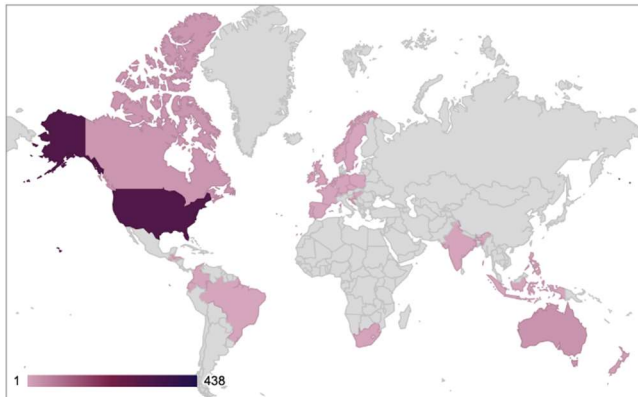


In 2020, the Cushing's Support and Research Foundation (CSR) formed a patient advisory committee to discuss topics we felt needed to be introduced into the framework of Cushing's care. A multiple question survey was developed using the substantial notes from these meetings, and the survey was distributed to our membership. There was about a 10% response rate, and after much enthusiasm and sharing this data far and wide for two years, we decided to do another one in 2022 (scan QR code or visit <https://csrf.net/reportsandpresentations>). At that point we were already pretty sure that developing a patient registry was in our future, and began conversations with our Medical Advisory Board and others about the feasibility of CSR hosting and "owning" this type of database.



In 2023 we designed a third survey, similar to the other two but intentionally created for a broader global audience. Several international advocacy organizations partnered with CSR to distribute the survey, and within weeks we had over 400 responses from 38 countries. CSR has presented pieces of this data at two professional conferences in 2024, and you are now in possession of the final report that contains the full data (copies of the posters can be found by scanning the QR code above). We have inserted certain datapoints into the introduction of this report, and the remainder of the survey data is contained in the charts that follow.



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report, and the remainder of the survey data is contained in the charts that follow.

We are grateful to every single person who took the time to answer this large volume of questions. We are humbled every day to know that going through Cushing's leads so many of us to want to change things so others do not have to suffer the way we did. At the time of this report's release, CSR is about 2/3 of the way through a patient registry build with a soft launch projected for February 2025. The registry will allow us to fully professionalize these concepts and studies, and the data sets produced will be used by researchers around the world. **Thank you.**

### METHODOLOGY

This report represents a significant quality of life study designed by CSR in 2023. It was distributed globally through partnership with many international advocacy organizations including the Pituitary Foundation Ireland, the Australian Pituitary Foundation, and the World Alliance of Pituitary Organizations (WAPO). Surveys were translated and offered in French and Spanish to expand access.

## DEMOGRAPHICS

A total of 435 respondents from 38 countries successfully completed the survey. Women dominated the ratio with 400 (91.95%) to men's 32 (7.36%), with two non-binary individuals and one trans woman rounding it out. More than half of survey-takers were in the 40-59 age range, which supports current data in literature. Distribution looked like this:

<b>18-29</b> 8.97%	<b>40-49</b> 29.43%	<b>60-69</b> 14.25%
<b>30-39</b> 17.01%	<b>50-59</b> 26.90%	<b>70+</b> 3.45%

As we built the survey, we considered that the "ethnic background" question probably looked different in non-US countries. We did our best, but in the future we will do better to try to ensure that everyone is represented fully. For this survey, our breakdown looks like this:

<b>86.9%</b> Caucasian	<b>2.30%</b> Asian
<b>6.44%</b> more than one / other	<b>1.38%</b> African / Black
<b>2.76%</b> Hispanic / Latino	<b>0.23%</b> Native / Indigenous

Pituitary was the most prevalent source of Cushing's in this study (76.21%) with adrenal coming in second (16.26%). About 4% of people had a diagnosis but were still testing to find the source, and about 1% each reported exogenous Cushing's, autonomous cortisol secretion (MACS/ACS), ectopic in the lung, and ectopic elsewhere.

When these 435 respondents filled out the survey, two thirds (66.44%) of them reported that they had successful surgery and were in remission, 12.65% were in recurrence or still active after unsuccessful surgery, and about 6% had been diagnosed but had not yet had surgery. Around 2% of participants were either waiting for radiation to work, on cortisol-controlling medication, or had an exogenous source. Around one tenth (9.43%) of responses were from people who listed more than one status, in most cases because a first surgery did not work or they were in recurrence.

Eight people did not list their year of diagnosis, but of the rest, 21.31% were within two years of their diagnosis, 27.40% were 2-5 years out, 23.65% were 5-10 years out, 20.84% were 10-20 years out, and 6.79% were answering the survey with more than 20 years since their diagnosis.

## SIGNS AND SYMPTOMS

The majority of us (84.60%) agreed that looking at symptoms as "part of a package" instead of individually is vital for earlier screening. Even a self-aware person can be overwhelmed by the number and severity of comorbidities that Cushing's Syndrome brings, and it's difficult for almost all of us (93.10%) to understand this complicated diagnosis, especially in the beginning. It's no surprise that trying to manage those complex symptoms negatively impacts nearly everyone (95.86%) too.

We have explored some of the less-commonly reported signs, symptoms, and long-term residual effects of Cushing's in this survey. We know that there is room to do a much more thorough job of this and are motivated by the many comments that shared great ideas to include in symptom studies through the registry.

Changes to our physical appearance are a top concern, and it goes way beyond simply how we look. Sometimes people we know don't recognize us in active Cushing's (68.51%), we often feel rejected by our friends (69.66%), and three-quarters (74.94%) of survey respondents identify with the classic, grotesque image of the "Cushing's phenotype" we find when we search online for information about this disease.

Brain fog, cognitive impairment, and physical limitations affect our careers and the volume of work we are able to do; about 30% of respondents said they have lost motivation to do their jobs. Just over 40% are still motivated to do the job, but their effectiveness has been reduced by Cushing's. Almost half of us (47.13%) report a temporary interruption in work because of this illness, while about a third (31.26%) have had to make the difficult decision to quit their job. Struggling to keep up when you previously thrived in your career strikes at our identity and makes us question everything; 59.54% of us have found ourselves in this position to some degree.

## **DIAGNOSIS**

Sometimes the biggest challenge is getting the diagnosis! CSRF intends to use its research platform to further explore what we mean, and what doctors think, when we talk about "how long we had it before we got a diagnosis". The published average delay to diagnosis is listed as 5-7 years in peer-reviewed literature, and respondents' answers reflected that:

**26.7%** less than two years to diagnosis

**24.1%** 5-10 years to diagnosis

**28.4%** 2-5 years to diagnosis

**20.8%** more than 10 years to diagnosis

We need better screening programs, and patients are unanimous that primary care providers must be educated and supported. We're *nearly* unanimous that obesity doctors (97.70%) and gynecologists (93.33%) receive education and support as well. CSRF has recently broadened its scope of professional outreach due to this kind of feedback.

Overall, we are optimistic that things will get better (82.53%), but we want to have realistic expectations. For the best possible outcome with this complicated disease in any of its forms, it's clear that we must have the full picture so we can weigh our options and make the best choices for ourselves and our lives.

## **LIMITATIONS**

As we build the registry and look back on the way these and earlier survey questions were designed, we see so much room for improvement! We'll look at it as progress, learning to be more specific to be more effective. Here are some additional observations to share with you, to give you an idea of some back-end logistical work we did to present final results to you:

-We found three respondents who listed themselves as still seeking a diagnosis, but they answered questions about the post-treatment period. We removed those few files to ensure that only responses from people who listed a diagnosis would be included. In the future, we can improve qualification questions at the beginning of a survey.

-A related thought would then be – do undiagnosed patients, or those with “non-neoplastic endogenous” Cushing’s Syndrome, need a platform, and what would it look like?

-There were many questions where “n/a” did not need to be an option, but it was used by some people. It is a very imperfect method, but for this report we decided to combine “no” and “n/a” responses into one column. If you, Reader, have any questions about individual responses, we will be happy to get on a zoom with you and show you the raw data and how we calculated certain percentages.

-There were four individual questions about how long it took to reach diagnosis with no way to limit a respondent to just one choice, and they should have been combined into one single question. We ended up with 13 respondents who chose more than one option, and three who did not choose any option. Because of this, we excluded those 16 for this question ONLY, to end up with:

**<2 years = 26.73%** (112/419)

**5-10 years = 24.11%** (101/419)

**2-5 years = 28.40%** (119/419)

**>10 years = 20.76%** (87/419)

-The question about the type of Cushing’s a respondent has did not include enough options to ensure everyone sees themselves in at least one. The question about current status of Cushing’s needs more options as well, and should require at least one answer.

-We go back and forth among tenses – have, had, have or had – and it might have been confusing to answer questions that bounced back and forth from active Cushing’s to remission.

-Our coverage of adrenal insufficiency (AI) was sparse – we only asked about how you received information about it, and if you had permanent AI now. It’s a huge topic that deserves future exploration. If you are interested in joining a registry to contribute your experience with AI, please check out the myAI registry sponsored by the National Adrenal Diseases Foundation (NADF) by scanning this QR code or by visiting the website:



**<https://www.nationaljewish.org/clinical-trials/myai-registry-for-people-with-adrenal-insufficiency>**

-We polled ourselves about some of the things we don’t feel are well understood or represented in current literature, but we missed an opportunity to explore some of the positive things that can come out of this experience. Having Cushing’s changes a person, but oftentimes recovery *also* brings clarity, resolve, autonomy, courage, and acceptance. Encouragement and a balanced outlook must be present whenever we talk about this disease and what it does to us. If we’re going to share our problems, we must also have some solutions in mind!

**And now, the data:**

PHYSICAL	YES or AGREE	NO, DISAGREE, N/A
I have or did have leg and hip muscle weakness.	90.34%	9.66%
I lost physical strength with Cushing's.	97.24%	2.76%
I experience(d) pain.	91.26%	8.74%
I have problems with vertigo that I believe are from Cushing's.	45.06%	54.94%
After Cushing's I have bad balance.	62.53%	37.47%
I suspect I have had an increase in dental problems because of Cushing's.	55.86%	44.14%
I have not had any dental issues related to Cushing's.	38.62%	61.38%
I have or have had sores on my scalp that I believe are related to Cushing's.	30.34%	69.66%
I was or am diagnosed with peripheral neuropathy and believe it is from Cushing's.	28.05%	71.95%
I do not or did not have the classic Cushing's appearance and I feel like that delayed my diagnosis.	28.97%	71.03%
People do not or did not recognize me after surgery.	30.80%	69.20%
The classic Cushing's image is harmful because not every patient has stretch marks, a hump, or extreme weight gain.	69.89%	30.11%
I experience(d) insomnia.	90.34%	9.66%
I went or currently go to a dermatologist because of very bad acne or other skin conditions from Cushing's.	35.63%	64.37%

DELAYS TO DIAGNOSIS	YES or AGREE	NO, DISAGREE, N/A
I experienced fat shaming or bias in my quest for diagnosis.	79.54%	20.46%
I experienced gender bias in my quest for diagnosis.	34.94%	65.06%
I have had to fight my insurance company or healthcare provider for one or more treatments I needed for Cushing's.	44.60%	55.40%
I have had an unnecessary surgery due to not being diagnosed properly with Cushing's.	16.09%	83.91%
My non-specialist doctors do or did not seem to understand how to interpret cortisol lab results.	64.83%	35.17%
I have experienced a delay in care when a specialist and my General Practitioner (or Internist, or Primary Care Provider) have both stated that an issue was not their responsibility and referred that care to the other.	56.55%	43.45%

SUPPORT	YES or AGREE	NO, DISAGREE, N/A
Beyond the medical care team, I believe it “takes a village” to support a Cushing’s patient – family, friends, workplace, etc.	97.93%	2.07%
I attend or have attended a support group specifically for Cushing’s.	37.24%	62.76%
I have not but wish I could attend a support group.	58.62%	41.38%
I would like to have access to an online 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.	91.49%	8.51%
It is beneficial to share experiences with other patients.	97.93%	2.07%
A "peer sister" or "peer brother" to guide a patient along the way would be helpful.	94.25%	5.75%
I work with a mental health therapist.	39.54%	60.46%
I do not speak with a mental health therapist because of negative stigma.	8.51%	91.49%
I do not speak with a mental health therapist because of financial barriers.	29.66%	70.34%
I need or needed a caregiver in active Cushing's to help with things like bathing, shopping, household chores.	47.59%	52.41%
I need a caregiver's help now after Cushing's to help with personal tasks and errands.	34.71%	65.29%
I am curious about service and emotional support animals and how to get one.	47.82%	52.18%
I have access to an online patient portal where I can see my labs, scans, and communicate with my medical team.	78.39%	21.61%

COPING	YES or AGREE	NO, DISAGREE, N/A
I am familiar with the Spoon Theory, the pain/price index, or another energy management analogy used by patients with chronic illnesses	46.44%	53.56%
There are so many negative things happening with Cushing's that it can be difficult to determine what is related and what is not.	95.17%	4.83%
I feel that I need to learn how to retrain my brain to not always expect the worst, or for something else to go wrong, because that is how life has felt with Cushing's.	85.98%	14.02%
Before surgery I found so many things stressful, and it was difficult to cope.	80.92%	19.08%
After surgery I have found so many things stressful, and it has been difficult to cope.	64.83%	35.17%

OPINIONS	YES or AGREE	NO, DISAGREE, N/A
It bothers me to not know why I got Cushing's in the first place.	77.01%	22.99%
Cushing's can be lonely.	97.24%	2.76%
Determining what is "normal" after diagnosis is difficult.	98.85%	1.15%
I think visits to other specialists like pulmonologists and cardiologists should be part of the standard of care.	90.80%	9.20%
I believe that validating the patient experience is one of the most important things doctors can do.	97.70%	2.30%
Just because my blood test results fall in normal ranges, that does not mean my symptoms are gone or that I am ok.	94.02%	5.98%
I struggle to stay compliant with my medication dosing routine every day.	27.13%	72.87%
I believe that all the various names for high cortisol lead to misinterpretation, self-diagnosis, and confusion.	72.64%	27.36%
The patient voice and experience must be included in the planning and development of any new product, service, treatment, or clinical trial that is intended for our community.	98.62%	1.38%
This is a disease where it seems that most patients must get very sick before it can be diagnosed and treated.	97.47%	2.53%
I wish I could get all my doctors to the same table to discuss my case and create a plan across their specialties.	88.28%	11.72%
It is exhausting to be a full time patient to so many doctors.	91.72%	8.28%
I've been called a hypochondriac.	52.41%	47.59%
I believe to some degree that chronic stress throughout my life might have caused my tumor.	54.02%	45.98%

COGNITION AND NEUROPSYCHOLOGY	YES or AGREE	NO, DISAGREE, N/A
My job depends or depended on my ability to learn and retain information; cognition impairment affects this.	79.77%	20.23%
My short-term memory has been negatively impacted.	89.20%	10.80%
My long-term memory has been negatively impacted.	70.11%	29.89%
Memory problems have led me to use adaptations such as lists and notes to myself, and I did not do this before.	80.92%	19.08%
I have had neuropsychological testing and I would recommend it to any patient who has access to it.	19.54%	80.46%

RELATIONSHIPS	YES or AGREE	NO, DISAGREE, N/A
Cushing's has changed expectations and needs in my closest relationships.	88.05%	11.95%
You can almost literally be a different person after treatment, and that can cause challenges with relationships where you once had a clearly defined role and now it's different.	73.33%	26.67%
My children seem or seemed negatively impacted by my sickness.	41.38%	58.62%
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.	50.34%	49.66%
Relationships have suffered because I lost respect for people who refused to believe my illness.	57.24%	42.76%
I'm worried my marriage will end because of this experience.	21.61%	78.39%
My marriage or long-term relationship did not survive Cushing's.	19.77%	80.23%
My partnership/marriage has gotten stronger as we have gone through this journey together.	44.60%	55.40%
It is helpful and important to the patient for their loved ones to be present throughout their journey, even if they don't know what to do.	98.62%	1.38%

DIET	YES or AGREE	NO, DISAGREE, N/A
I would like to improve nutrition absorption problems associated with Cushing's.	84.60%	15.40%
If there were dietary changes I could make that would help with stamina, energy, and brain fog, I would do it.	97.70%	2.30%
I would consider an anti-inflammatory diet if it could truly help with arthritis and joint pain.	87.59%	12.41%
I recognize that I do not know how to start a healthy diet after having bad habits for years.	26.21%	73.79%
I would consider a diet that can reduce gastrointestinal issues related to Cushing's.	79.54%	20.46%
I struggle with diet and exercise.	69.20%	30.80%
I tried or considered extreme diet or exercise to lose weight while in active Cushing's	75.40%	24.60%
I am very knowledgeable about healthy food and how it plays a direct role in my health.	84.60%	15.40%
I would follow an exercise plan adapted for physical limitations and weak muscles.	92.41%	7.59%



MENTAL HEALTH	YES or AGREE	NO, DISAGREE, N/A
I believe that my emotional and mental health is just as important as my physical health.	99.31%	0.69%
Mental health support should be part of a treatment “package” recommended for all patients.	99.31%	0.69%
I experience or did experience anxiety and/or depression.	95.86%	4.14%
There is a need to process trauma afterwards.	91.95%	8.05%
I have developed excuses for my feelings and behaviors rather than validating the disease and healing process and being kind to myself.	61.15%	38.85%
I believe that therapy can be helpful even if a patient has good coping skills.	95.63%	4.37%
I have supportive family and friends, but that does not prevent me from having negative thoughts and feelings.	90.34%	9.66%
Apathy is sometimes stronger than symptoms of depression.	73.79%	26.21%
I have had suicidal thoughts.	50.57%	49.43%
Grief has been constantly present from diagnosis to recovery.	72.18%	27.82%
I feel or have felt that my health problems are all-consuming.	90.34%	9.66%

ADRENAL INSUFFICIENCY	YES or AGREE	NO, DISAGREE, N/A
I have not been given detailed information about adrenal insufficiency from my clinical team other than “double your dose for sick days”.	49.43%	50.57%
My clinical team has given me excellent, detailed information about how to manage adrenal insufficiency after successful surgery.	31.95%	68.05%
I have learned the majority of what I know about how to manage adrenal insufficiency from other patients instead of my doctor.	57.24%	32.76%
I have permanent adrenal insufficiency now because of Cushing’s.	32.64%	67.46%

MEDICATIONS AND DEVICES	YES or AGREE	NO, DISAGREE, N/A
I am interested in learning more about the cortisol-lowering medications available to Cushing’s patients.	60.92%	39.08%
I am interested in learning more about pumps, patches, test kits, and other devices in the pipeline.	77.47%	22.53%

POST-TREATMENT	YES or AGREE	NO, DISAGREE, N/A
I think there is a perception by most people that everything does or should go back to normal after surgery.	91.49%	8.51%
I was not prepared for what it was going to be like after surgery.	72.41%	27.59%
Knowing what to expect the first month after surgery was a big concern for me.	78.62%	21.38%
Following surgery, I felt that I had little to no support from the medical team I'd been with throughout my diagnosis and surgery.	42.07%	57.93%
Cortisol withdrawal after a successful surgery is something that makes me nervous / afraid.	66.90%	33.10%
I was told I would be all better and back to work about 6 weeks after surgery.	47.82%	52.18%
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.	87.36%	12.64%
I wish I had been told before surgery about hydrocortisone tapering and what to expect.	60.69%	39.31%
After surgery, I have recovered back to pretty much my "old normal".	15.17%	84.83%
After surgery, "old normal" is gone and I'm still trying to determine what my "new normal" really looks like.	75.17%	24.83%
After surgery, I am vigilant for any new sign of illness or return of high cortisol.	81.61%	18.39%
All of my pituitary hormones have been tested to see if I need to supplement anything.	57.70%	42.30%
Healing is a slow process and does not only include normalization of cortisol.	94.94%	5.06%
I want and need to gain confidence back about my body and appearance.	90.34%	9.66%

SECONDARY HEALTH ISSUES	YES or AGREE	NO, DISAGREE, N/A
I have had a hysterectomy because of Cushing's.	14.71%	85.29%
I have or did have low libido from Cushing's.	79.77%	20.23%
I am or was diagnosed with diabetes insipidus / arginine vasopressin deficiency	36.09%	63.91%
It was or is difficult to manage my diabetes insipidus.	19.08%	80.92%
I developed kidney disease because of Cushing's.	12.41%	87.59%

LONG-TERM	YES or AGREE	NO, DISAGREE, N/A
I want to know long-term health data (20+ years), even if it might be scary.	95.63%	4.37%
I would like to know how patients are doing who had radiation 20 or more years ago.	65.29%	34.71%
I am concerned about long-term cardiovascular damage from Cushing's.	85.75%	14.25%
I am concerned about negative impact from Cushing's on white and grey matter in the brain.	88.05%	11.95%
I wonder if the roller coaster ever subsides – I feel like I'm ok some days but barely able to function on others.	86.21%	13.79%
I believe that recovery from Cushing's doesn't truly begin until a patient is completely weaned off steroid replacement.	51.03%	48.97%

FAITH AND OUTLOOK	YES or AGREE	NO, DISAGREE, N/A
This experience has negatively affected my faith in my God/religion/greater power.	21.84%	78.16%
My faith has been strengthened throughout the challenges of this disease.	43.22%	56.78%
Cushing's has caused me to learn new ways to manage stress and find peace that help me in other areas of my life.	72.87%	27.13%
I have decided to take better care of myself as a result of this experience.	76.32%	23.68%
My outlook on life has become more focused and intentional after surviving this battle with Cushing's.	74.02%	25.98%



Leslie Edwin, President – [leslie@csrf.net](mailto:leslie@csrf.net)

Gretchen Jordan, Associate Director – [gretchen@csrf.net](mailto:gretchen@csrf.net)