



2022 UPDATE ON DEEPER QUALITY OF LIFE (QoL) TOPICS – MEMBERSHIP SURVEY

Prolonged exposure to excessive cortisol can be devastating to the brain and body, but there are often barriers to accurate education, timely diagnosis, and appropriate treatments. The Cushing's Support & Research Foundation (CSRFS) is a US-based 501c3 non-profit membership organization run by patients since its founding in 1995, and we support those affected by Cushing's Disease and Syndrome along with their medical providers and caregivers. Our team consists of an Executive Board, a Medical Advisory Board, a Patient Advisory Committee, a Corporate Council, and volunteers.

One of CSRFS's goals is to validate patients' lived experiences by regularly collaborating on projects to share with medical professionals and other stakeholders in the Cushing's community. Our hope is to paint a larger picture for anyone caring for a Cushing's patient. We know it's a lot! We live it every day, so better understanding and validation are very meaningful when we're struggling. We know that our providers could never follow us so intimately to observe these details themselves, but we want you to know about them because often times they are barriers to us achieving our best possible quality of life after enduring the burden of this rare disease.

In early 2022, a committee of CSRFS patient members held a series of workshops to create a survey that explored QoL issues that go beyond typical clinical and lab reports and are often overlooked and underreported in research. The survey was completed online by 175 CSRFS members (almost a 10% response rate in less than a week!) and presented at the European Congress of Endocrinology in Milan May 2022. Some of our findings are included in this report.

Many patients are personally touched when they see the results of our committee-created projects because the data provides evidence that they are not alone in the challenges they face. While we ask for better treatment, support, and validation from those who work with us, we also support ourselves and each other.

Thank you for taking the time to consider the information in the following pages, and if you have any questions or would like more information, please visit our website at csrf.net or send us an e-mail at cushinfo@csrf.net.

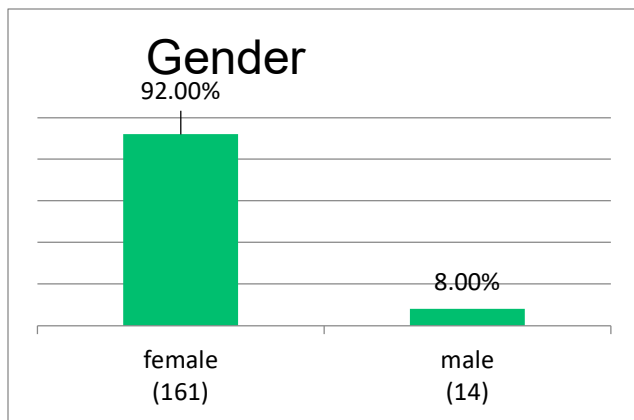
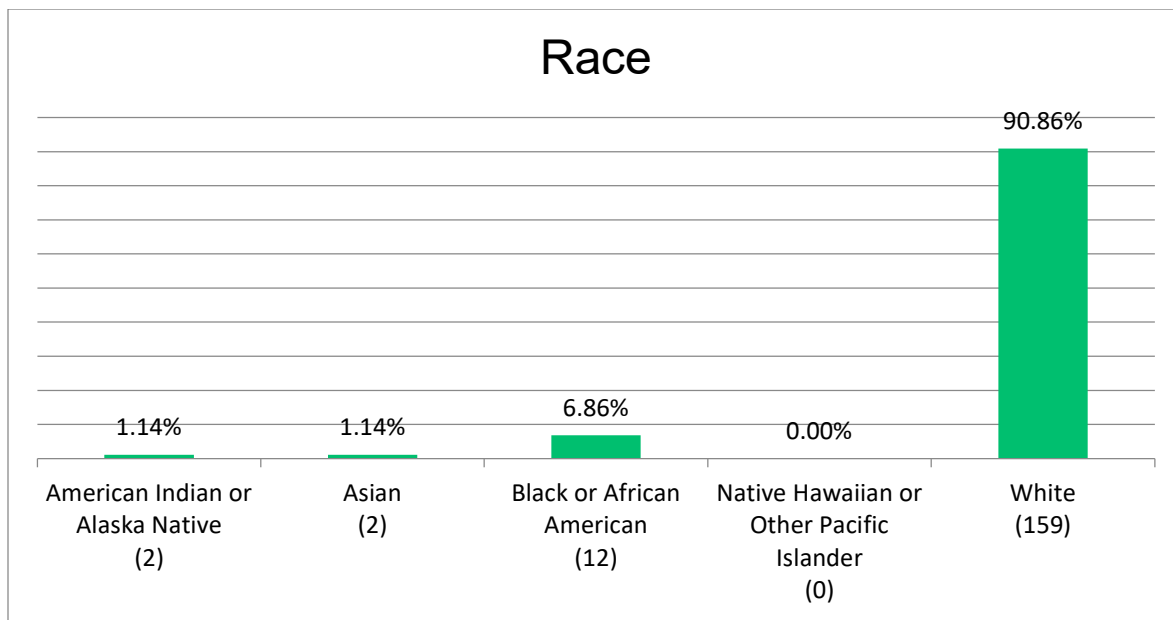
-CSRFS Membership, July 2022

The following information was collected from 175 patient members of the Cushing’s Support and Research Foundation in May 2022. The survey was sent via e-mail to 1,922 active patients, and the robust 9.1% response rate was achieved in just five days.

DEMOGRAPHICS:

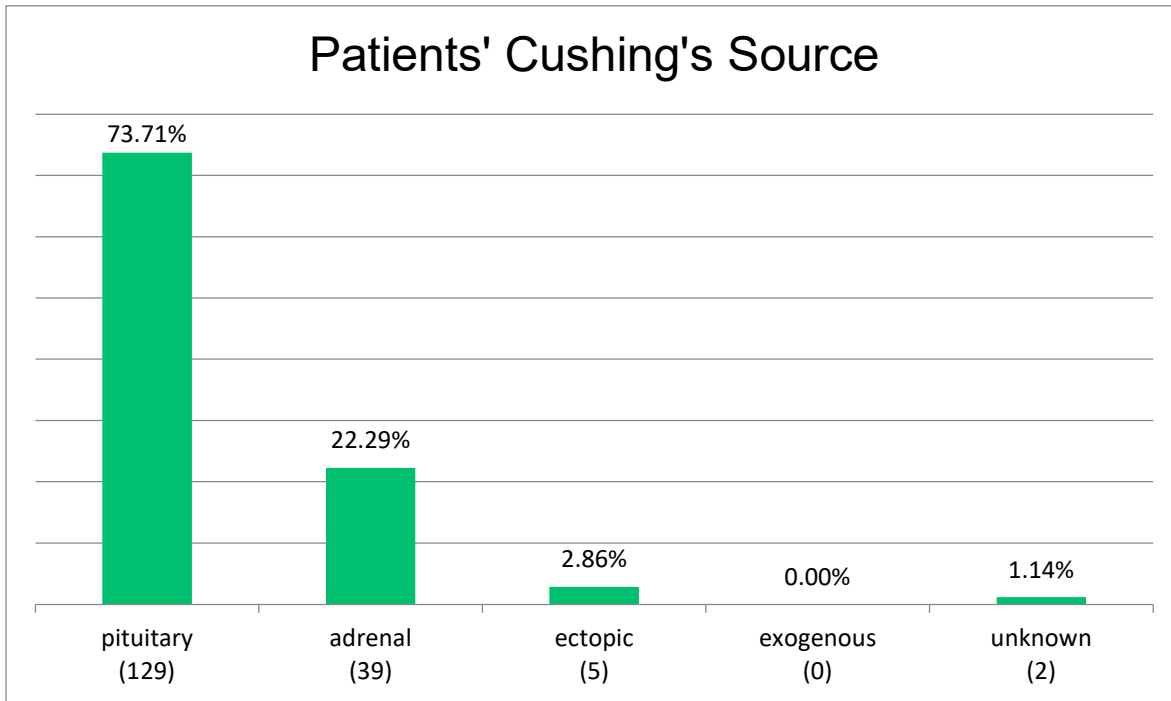
The majority of our respondents came from the United States, with 27 international participants:

US	148	UK	5
Canada	9	Other	7
Australia	6		

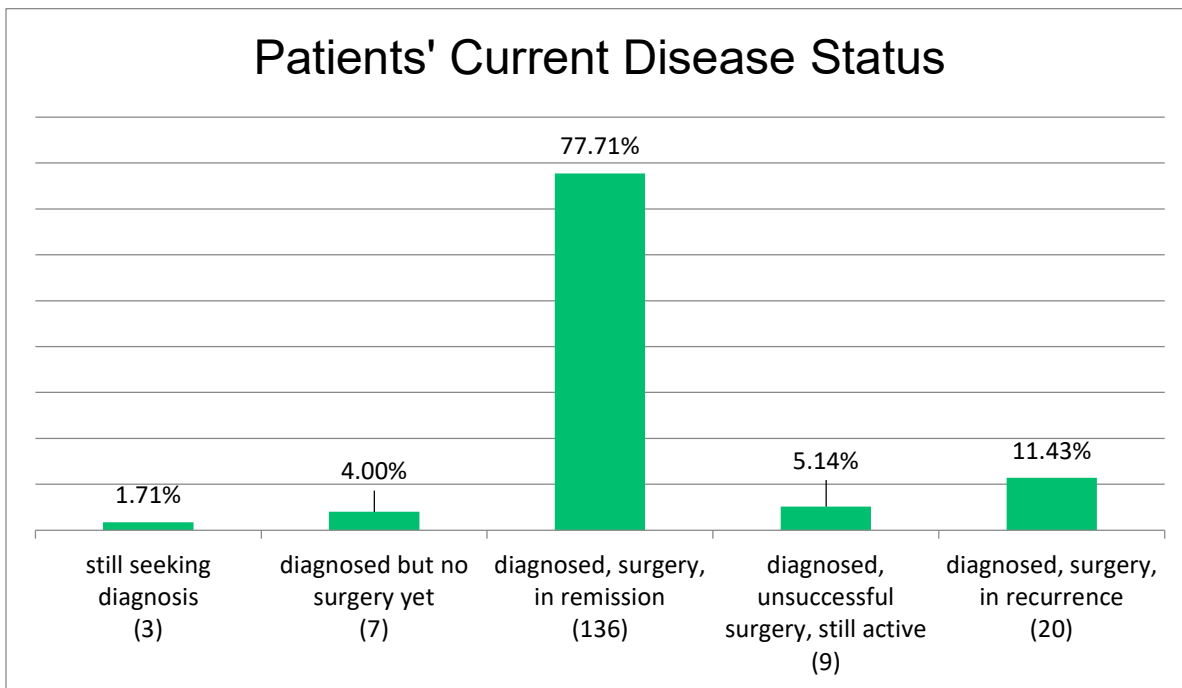


PARTICIPANT AGES RANGED FROM 22-88, WITH AN AVERAGE OF 54.

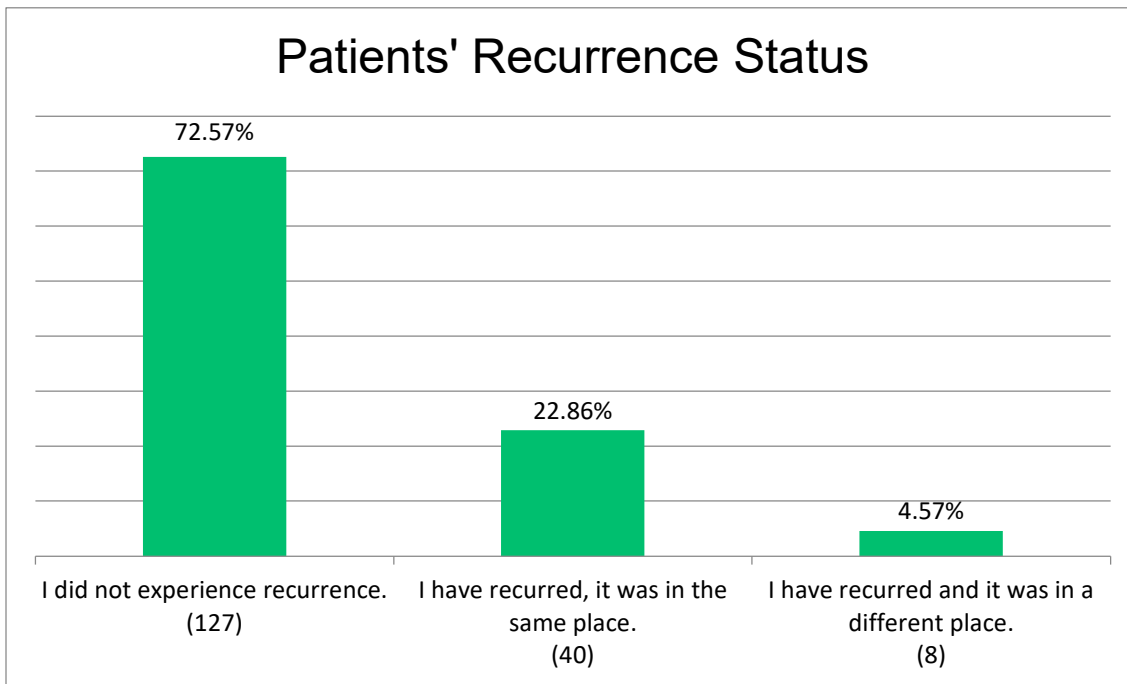
Patients' Cushing's Source



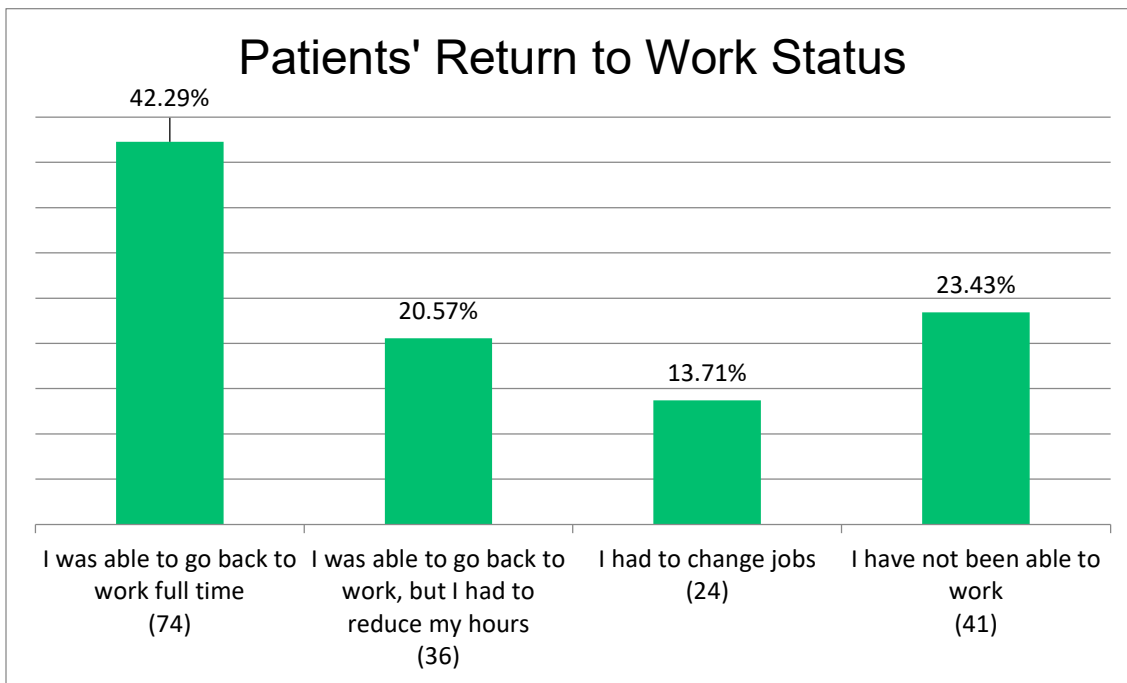
Patients' Current Disease Status



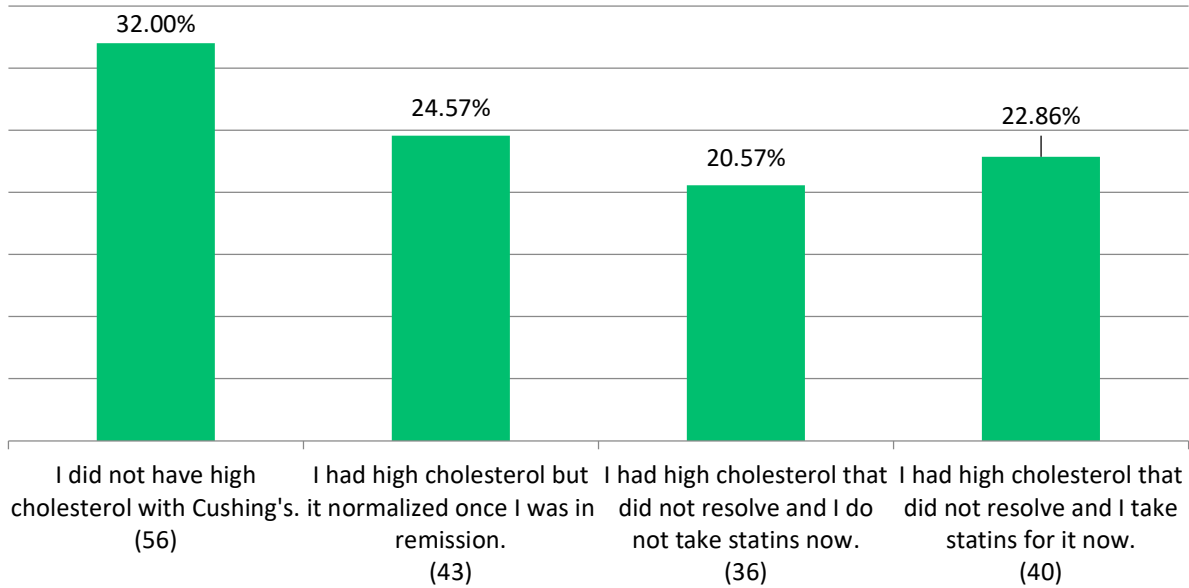
Patients' Recurrence Status



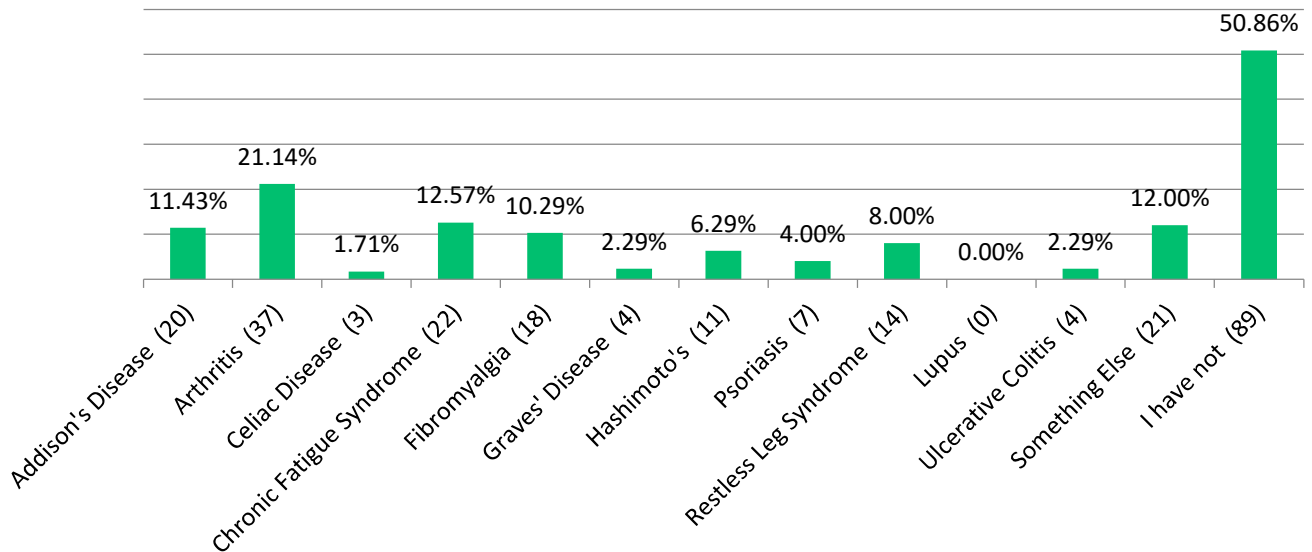
Patients' Return to Work Status

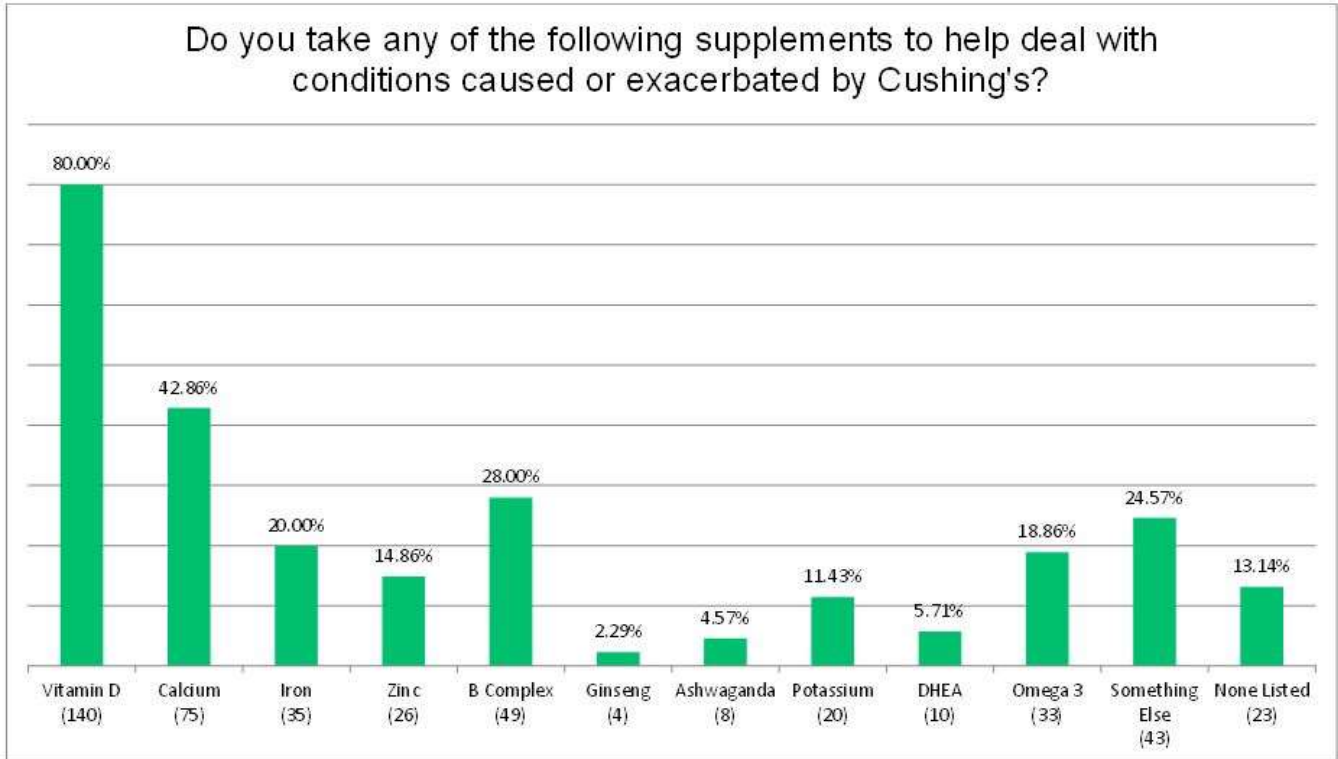


Patients' Experience with High Cholesterol During and After Cushing's



Did you have any of the following autoimmune disorders that were unmasked by resolving your high cortisol, or new after resolution of Cushing's?





Under “something else”, the most common additions were:

Magnesium (15)

Multivitamins (9)

Biotin (6)

Turmeric (5)

Vitamin C (4)

Vitamin K (4)

Folic Acid (3)

Probiotics (3)

Vitamin E (3)

The following survey questions are the outcome of CSRFB patient committee QoL workshops. While we accept that “scientific statistical significance” is somewhere around 2/3 of respondents, we know that with a rare disease, even 1/3 or 1/2 of patients experiencing the same thing will be significant to those searching for an answer or option.

PROFESSIONAL SUPPORT	Yes		No		Total
Following surgery, I felt that I had little to no support from the medical team I'd been with throughout my diagnosis and surgery.	24.00%	42	76.00%	133	175
I understand that no single doctor can or does know everything.	98.86%	173	1.14%	2	175
My non-specialist doctors did not seem to understand how to accurately run blood, urine, and saliva testing for high cortisol.	58.86%	103	41.14%	72	175
I have access to a patient portal where I can see my labs, scans, and communicate with my medical team.	84.57%	148	15.43%	27	175

DIET AND EXERCISE	Yes		No		Total
I tried extreme diet or exercise to keep the weight off while in active Cushing's	65.71%	115	34.29%	60	175
I practice intermittent fasting.	17.71%	31	82.29%	144	175
I am very knowledgeable about healthy food and how it plays a direct role in my health.	90.86%	159	9.14%	16	175

PHYSICAL PRESENTATION	Yes		No		Total
My body smelled bad while in active Cushing's.	34.29%	60	65.71%	115	175
People did not recognize me with Cushing's.	66.29%	116	33.71%	59	175
People did not recognize me after surgery.	31.43%	55	68.57%	120	175
I felt like I almost had a repellent, repulsive "aura" in active Cushing's.	49.14%	86	50.86%	89	175
The classic Cushing's image is helpful because I saw myself in it and it was useful to help explain what was happening to me.	72.57%	127	27.43%	48	175
The classic Cushing's image is harmful because not everyone looks like that and it perpetuates the false narrative that we're all going to be overweight with stretch marks and a hump.	51.43%	90	48.57%	85	175

POST-SURGERY	Yes		No		Total
Cortisol withdrawal after a successful surgery is painful and dangerous.	73.71%	129	26.29%	46	175
After Cushing's I have bad balance.	45.14%	79	54.86%	96	175
I have been diagnosed with PTSD or CPTSD as a result of my Cushing's.	9.71%	17	90.29%	158	175
I have not been diagnosed, but I believe I have PTSD or CPTSD from Cushing's.	35.43%	62	64.57%	113	175
I have been diagnosed with new ADD / ADHD after Cushing's.	7.43%	13	92.57%	162	175
I experienced some symptoms going away immediately after remission, while some remained much longer.	86.86%	152	13.14%	23	175
Healing is a slow process and does not only include normalization of cortisol.	96.57%	169	3.43%	6	175
I have recovered back to pretty much my "old normal".	29.14%	51	70.86%	124	175
"Old normal" is long gone and I'm still trying to determine what my "new normal" really looks like.	72.00%	126	28.00%	49	175

HARM AND BIAS	Yes		No		Total
I've been called a hypochondriac.	32.57%	57	67.43%	118	175
I was told I would be all better and back to work about 6 weeks after surgery.	44.00%	77	56.00%	98	175
I experienced humiliation and/or rejection from people I knew while I was in active Cushing's.	56.57%	99	43.43%	76	175
I experienced fat shaming or bias in my quest for diagnosis.	58.86%	103	41.14%	72	175
I experienced gender bias in my quest for diagnosis.	20.57%	36	79.43%	139	175
I experienced racial bias in my quest for diagnosis.	1.71%	3	98.29%	172	175
It's more acceptable to be overweight if you are a man.	62.86%	110	37.14%	65	175

PERSONAL OBSERVATIONS AND OPINIONS	Yes		No		Total
This is a disease where you must get very sick before it can be diagnosed and treated.	90.29%	158	9.71%	17	175
"Cured" is a dangerous word.	73.71%	129	26.29%	46	175
I am proud to call myself cured because this was such a struggle, and I endured.	52.00%	91	48.00%	84	175
I believe that validating the patient experience is one of the most important things my doctors can do.	96.00%	168	4.00%	7	175
I am frustrated by one-size-fits-all "normal ranges" of hormone levels in the blood that I do not feel are accurate to me personally.	64.00%	112	36.00%	63	175
I would have loved a "peer sister" or "peer brother" to guide me along the way.	88.00%	154	12.00%	21	175
I believe it is important to educate primary care providers about this condition.	99.43%	174	0.57%	1	175
I believe it is important to educate obesity doctors about this condition.	100.00%	175	0.00%	0	175
I believe it is important to educate gynecologists about this condition.	98.29%	172	1.71%	3	175
I believe to some degree that chronic stress throughout my life might have caused my tumor.	45.71%	80	54.29%	95	175
I believe that the cost for blood, urine, and saliva tests, even to "rule out", is very small compared to the detrimental cost to my health from a delayed diagnosis.	95.43%	167	4.57%	8	175

PEER-TO-PEER ADVICE	Yes		No		Total
Memory problems have led me to use adaptations such as lists and notes to myself, and I did not do this before.	73.14%	128	26.86%	47	175
I have had neuropsychological testing because of Cushing's.	24.57%	43	75.43%	132	175
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.	89.14%	156	10.86%	19	175

CHALLENGES	Yes		No		Total
Just because my blood test results fall in normal ranges, that does not mean my symptoms are gone or that I am ok.	83.43%	146	16.57%	29	175
I had to fight my insurance company on one or more treatments I needed for Cushing's.	24.57%	43	75.43%	132	175
I believe that all the various names for high cortisol lead to misinterpretation, self-diagnosis, and confusion.	60.57%	106	39.43%	69	175
I feel that my health problems are all-consuming.	52.57%	92	47.43%	83	175
I consider myself hypervigilant for any new sign of illness or return of high cortisol.	75.43%	132	24.57%	43	175
I have ongoing pain.	52.00%	91	48.00%	84	175
I have ongoing problems with stamina.	76.00%	133	24.00%	42	175
I have long-term memory problems.	65.14%	114	34.86%	61	175
I still find so many things stressful, and it is difficult to cope.	52.57%	92	47.43%	83	175
I needed a caregiver in active Cushing's to help with things like bathing, shopping, household chores.	28.00%	49	72.00%	126	175
I need a caregiver's help now after Cushing's to help with personal tasks and errands.	16.00%	28	84.00%	147	175
I know that prolonged high cortisol can damage my DNA.	30.86%	54	69.14%	121	175
I struggle with body temperature regulation.	58.86%	103	41.14%	72	175

To view the data from the 2020 Patient Quality of Life Survey, please visit the following website or scan the QR code:

<https://csrf.net/wp-content/uploads/2020/12/PDF-SURVEY-DATA-for-newsletter.pdf>

