

CSRF In-House Patient Questionnaire Results

2020

	YES / I agree / I experienced		NO / I don't agree / I didn't experience		N/A / didn't affect me	
MENTAL HEALTH						
I believe that my emotional/mental health is just as important as my physical health.	98.88%	176	0.56%	1	0.56%	1
Mental health support should be part of a treatment “package” recommended for all patients.	98.31%	175	1.12%	2	0.56%	1
I experience(d) anxiety / depression.	91.57%	163	5.62%	10	2.81%	5
I believe that even if you’re coping well, you will probably still benefit from therapy.	91.01%	162	6.18%	11	2.81%	5
Cushing’s is lonely.	87.64%	156	10.11%	18	2.25%	4
There are so many negative things happening that you can never tell what’s caused or causing what.	87.64%	156	8.43%	15	3.93%	7
There is a need to process trauma afterwards.	87.08%	155	6.74%	12	6.18%	11
In the beginning, it is almost impossible to fully comprehend a Cushing’s diagnosis and everything that goes with it.	86.52%	154	10.11%	18	3.37%	6
I wish I could attend a support group.	74.72%	133	16.85%	30	8.43%	15
I need to figure out how to gain confidence back about my body and appearance.	70.79%	126	19.66%	35	9.55%	17
I feel that I need to learn how to untrain my brain when it wants to expect the worst after spending so long expecting something else to go wrong.	68.54%	122	21.91%	39	9.55%	17
RELATIONSHIPS						
Even if a loved one doesn’t know what to do, it is very helpful just to be present throughout the journey.	97.75%	174	0.00%	0	2.25%	4
Even having supportive family and friends does not always protect against negative thoughts and feelings.	94.94%	169	2.81%	5	2.25%	4
I can’t imagine going through this without the spouse/caregiver(s) that stood by my side.	76.97%	137	11.80%	21	11.24%	20
You can almost literally be a different person after treatment than you were before and during, and that can cause challenges with relationships where you once had a clearly defined role and now it’s different.	74.16%	132	12.92%	23	12.92%	23

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SPECIALISTS NEEDED / EDUCATION TARGETS						
I think more education should be focused on primary care providers because they tend to see our non-specific symptoms first.	97.19%	173	1.12%	2	1.69%	3
Beyond the medical care team, it frequently “takes a village” to support a Cushing’s patient – doctors, family, friends, workplace, etc.	91.01%	162	5.62%	10	3.37%	6
I think visits to other specialists like pulmonologists and cardiologists should be part of the standard of care to ensure other vital organs are not sustaining needless damage.	90.45%	161	6.74%	12	2.81%	5
It is vital that symptoms are considered as part of a package vs individually.	87.08%	155	8.43%	15	4.49%	8
I think there is a need for a team mentality and swift response for “non endocrine” symptoms that we suffer from after surgery that our “non specialist” doctors don’t or might not feel qualified to treat.	83.71%	149	5.62%	10	10.67%	19
We need a symptoms “compiler” so all issues can stop being considered individually.	83.15%	148	10.67%	19	6.18%	11
I was negatively impacted by the complexity of having multiple symptoms to manage.	83.15%	148	11.80%	21	5.06%	9
I wish I could get all my doctors to the same table to discuss my case and create a plan across specialties.	79.78%	142	11.80%	21	8.43%	15
It is exhausting to be a full time patient to so many doctors.	79.78%	142	10.11%	18	10.11%	18
LONG TERM EFFECTS						
I’m very interested in the long-term impact of Cushing’s on the brain and heart.	95.51%	170	3.93%	7	0.56%	1
Determining what is “normal” after diagnosis can get pretty warped.	93.82%	167	3.37%	6	2.81%	5
I’m curious about cognitive decline or improvement.	93.26%	166	5.06%	9	1.69%	3
I want to know what is physically happening to my brain during Cushing’s – does it shrink, do I lose grey matter, are neurons affected, is there anything to do to reverse these things, etc.	93.26%	166	5.06%	9	1.69%	3
I would love to know long-term health data (10+ years), even if it might be scary.	92.70%	165	4.49%	8	2.81%	5
The effects of long-term excess cortisol on the brain are scary.	91.57%	163	5.06%	9	3.37%	6
I think there is a perception by most people that everything does or should go back to normal after surgery.	89.89%	160	3.93%	7	6.18%	11

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(LONG-TERM EFFECTS, CONTINUED)	YES / I agree / I experienced		NO / I don't agree / I didn't experience		N/A / didn't affect me	
I want to stay optimistic that things will get better but it would be nice to know how realistic that is.	88.20%	157	5.62%	10	6.18%	11
I would like to hear more stories about people who have had one surgery or treatment and have been in long-term remission / cure since then (10+ years)	78.65%	140	17.42%	31	3.93%	7
I would like to know if my immune system is permanently impaired even though I have been in remission.	71.35%	127	16.29%	29	12.36%	22
Memory fog and crashing with the heat are concerns with AI.	67.42%	120	7.87%	14	24.72%	44
FUNCTIONAL EFFECTS						
I lost physical strength with Cushing's.	92.13%	164	7.30%	13	0.56%	1
I'm curious if there is any evidence of a trend for leg and hip muscle weakness and pain and overall stamina to ever get better.	88.20%	157	6.74%	12	5.06%	9
I experience(d) insomnia.	80.90%	144	16.85%	30	2.25%	4
I experience(d) pain.	79.21%	141	16.85%	30	3.93%	7
COGNITIVE EFFECTS						
I've had memory issues.	85.96%	153	11.80%	21	2.25%	4
Short-term memory has taken a hit.	82.02%	146	14.61%	26	3.37%	6
Loss of cognition can bring your life to a screeching halt, especially when your livelihood depended on it.	74.72%	133	7.87%	14	17.42%	31
I lost mental strength with Cushing's.	82.58%	147	14.61%	26	2.81%	5
I feel very unmotivated and only complete a portion of the volume of work I used to be able to do.	67.42%	120	27.53%	49	5.06%	9
DIET AND EXERCISE						
I would like to learn more about dietary changes I can make to address stamina, energy, and brain fog.	88.20%	157	6.74%	12	5.06%	9
I'm very interested in exercise adapted for my new physical limitations and weak muscles.	81.46%	145	7.87%	14	10.67%	19
I'd like to know if there's any way to combat the compromised nutrition absorption that comes with Cushing's.	78.65%	140	8.99%	16	12.36%	22

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(DIET AND EXERCISE, CONTINUED)	YES / I agree / I experienced		NO / I don't agree / I didn't experience		N/A / didn't affect me	
I'm curious if there is a truly effective anti-inflammatory diet that can help with arthritis and joint pain.	75.84%	135	11.80%	21	12.36%	22
I'm interested in learning about any diet that can make the GI issues related to Cushing's less impactful.	67.42%	120	14.04%	25	18.54%	33
OBSERVATIONS						
"Everybody's different" is frustratingly dismissive – there are commonalities we will inevitably share.	82.58%	147	10.67%	19	6.74%	12
Patients should give feedback at all steps of the value chain and work with pharma.	76.40%	136	5.62%	10	17.98%	32
Important for doctors to be sensitive to the lack of weight loss that can occur while taking steroids.	75.28%	134	7.30%	13	17.42%	31
I was not prepared for what it was going to be like after surgery.	74.72%	133	19.10%	34	6.18%	11
Knowing what to expect the first month after surgery was a big concern for me.	73.03%	130	20.22%	36	6.74%	12
I believe in alternative / non-Western medicine and therapies and would like to know more about any that could help relieve some of my symptoms that have science to back up their claims.	71.91%	128	21.91%	39	6.18%	11
I want to know more about all these supplements that promise adrenal and/or cortisol support.	70.22%	125	20.22%	36	9.55%	17
I am very interested in learning more about the medications available to Cushing's patients.	68.54%	122	17.42%	31	14.04%	25
Using a pill box or other method has worked for me to remain compliant on my meds.	67.98%	121	16.29%	29	15.73%	28
"HALF OR MORE"						
My sex drive has been negatively impacted.	64.61%	115	20.22%	36	15.17%	27
I actually feel very motivated to do my work but am physically and/or mentally unable to do it.	64.04%	114	26.97%	48	8.99%	16
I've gotten a lot out of sharing experiences with other patients.	63.48%	113	17.98%	32	18.54%	33
Apathy is sometimes stronger than symptoms of depression.	62.92%	112	21.35%	38	15.73%	28

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I wonder if the rollercoaster ever subsides – I still feel like I go from feeling fine one day to completely out of it the next, barely able to function.	62.92% 112	29.78% 53	7.30% 13
I know I will frequently be unable to follow a strict exercise regime, so I'd like to know if there are any simple things I could do throughout the day to still support my physical health when real exercise is not an option.	62.36% 111	23.03% 41	14.61% 26
I want to know more about osteoporosis and how to treat it.	61.80% 110	28.65% 51	9.55% 17
I am very interested in learning more about news on pumps, patches, test kits, and other devices in the pipeline.	61.24% 109	20.22% 36	18.54% 33
I was previously the light-hearted, cheerful, pace-setting center of the family.	59.55% 106	24.72% 44	15.73% 28
It bothers me a lot to not know why I got Cushing's in the first place.	58.99% 105	35.96% 64	5.06% 9
I struggle with diet and exercise, and as a result the way I feel about myself is negatively impacted.	58.43% 104	29.21% 52	12.36% 22
I learned the majority of what I know about AI from patient organizations or online forums run by patients.	57.87% 103	21.35% 38	20.79% 37
I previously thrived in a fast-paced corporate or governmental culture but now either struggle intensely with the same style or have had to give it up.	57.87% 103	23.03% 41	19.10% 34
Pre-diagnosis was harder than all other stages of the journey because it seemed hard to believe and therefore empathize or understand.	56.18% 100	38.76% 69	5.06% 9
I wish I had options to address the loss of sex drive that negatively affects our intimate lives.	55.62% 99	16.29% 29	28.09% 50
I was not offered any fine-tuned information for AI other than "when sick double your dose".	53.93% 96	25.28% 45	20.79% 37
Grief has been constantly present from diagnosis to recovery.	52.81% 94	42.70% 76	4.49% 8
I want to know more about how CBD and THC are being used to treat some of the symptoms I experience.	52.81% 94	37.64% 67	9.55% 17
I feel like once weaned off the steroids is the start of the real recovery time.	51.69% 92	19.66% 35	28.65% 51
I receive treatment at a center of excellence and can vouch for the benefit of having my specialists connected on the same system.	51.12% 91	29.78% 53	19.10% 34

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Would be nice to see how patients who received radiation are faring 20+ years later.	50.00%	89	4.49%	8	45.51%	81
I feel frustration not knowing, or knowing!, if I'm going to be on all these replacement and symptom meds for the rest of my life.	50.00%	89	20.22%	36	29.78%	53
"ABOUT HALF"						
I use coping methods such as journaling or meditation to deal with Cushing's.	49.44%	88	47.19%	84	3.37%	6
I was negatively impacted by losing hair.	48.88%	87	34.83%	62	16.29%	29
My spouse / SO and I need to learn to be more deliberate with open communication when stating our expectations and needs when it comes to the effects Cushing's has had on me and our relationship.	47.75%	85	15.73%	28	36.52%	65
I suspect I have had an increase in dental problems because of Cushing's.	47.75%	85	43.26%	77	8.99%	16
My relationship has gotten stronger as we have gone through this journey together.	46.63%	83	21.91%	39	31.46%	56
I developed excuses for my feelings and behaviors rather than validating the disease or healing process and being kind to myself.	45.51%	81	48.88%	87	5.62%	10
I experience(d) a nauseating feeling similar to sea sickness even after surgery.	45.51%	81	43.82%	78	10.67%	19
I wish I had been told how tapering would happen up front, and what to expect.	45.51%	81	30.34%	54	24.16%	43
Friends I would have considered the kind that would stick around lost touch while I was at my worst.	43.82%	78	46.07%	82	10.11%	18
I am in online patient forums and love them.	43.82%	78	30.90%	55	25.28%	45
I have not had any dental issues related to Cushing's.	43.26%	77	46.07%	82	10.67%	19
It gets harder with each round of treatments necessary and there's less hope for achieving any sort of "normal" the more efforts need to be made to get better.	42.70%	76	24.72%	44	32.58%	58
None of my other pituitary hormones were addressed after surgery (or before). I was put on hydrocortisone but nothing else.	42.70%	76	34.27%	61	23.03%	41
I suspect that I have PTSD.	41.57%	74	49.44%	88	8.99%	16

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I was made aware of which symptoms to report if they did not resolve after three months post-surgery.	41.01%	73	50.56%	90	8.43%	15
I would like to have access to an online patient forum that is actively moderated and things like diagnostics and treatment recommendations are strictly forbidden.	40.45%	72	39.33%	70	20.22%	36
I am interested in information about SSI Disability.	40.45%	72	32.02%	57	27.53%	49
"ABOUT A THIRD"						
I had pituitary Cushing's but did not have an IPSS.	39.89%	71	34.83%	62	25.28%	45
My children rallied for me, helping with adaptations and making me comfortable.	39.33%	70	15.17%	27	45.51%	81
Relationships suffered because I lost respect for people who refused to see my illness.	38.20%	68	42.70%	76	19.10%	34
I didn't have a great understanding of what diabetes insipidus was.	38.20%	68	26.97%	48	34.83%	62
I have had suicidal thoughts.	35.96%	64	54.49%	97	9.55%	17
I have had significant dental problems that seemed to come out of nowhere that I suspect were related to Cushing's.	35.96%	64	51.12%	91	12.92%	23
I did not have the classic Cushingoid appearance and I feel like that delayed my diagnosis.	35.96%	64	53.37%	95	10.67%	19
Adjusting to a new hormone replacement therapy is difficult and uncomfortable.	34.83%	62	19.66%	35	45.51%	81
I was impacted by a family that does not understand or has grown tired of a treatment process that has been going on for a long time.	32.58%	58	56.18%	100	11.24%	20
I've had more infections since my surgeries than before (UTIs, sinus, etc.)	32.58%	58	57.87%	103	9.55%	17
My children seemed negatively impacted by my sickness.	30.90%	55	29.21%	52	39.89%	71
I am in online patient forums and appreciate the resource but feel uneasy about the high rates of patient-to-patient diagnostics.	30.34%	54	34.27%	61	35.39%	63
I would like to speak with a therapist but I experience financial barriers.	29.21%	52	50.00%	89	20.79%	37
I ended up with permanent AI.	29.21%	52	33.71%	60	37.08%	66

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"ABOUT A QUARTER"						
Sleep disturbances have caused my spouse / SO and I to sleep in separate beds or make other accommodations that affect our intimacy.	26.40%	47	38.20%	68	35.39%	63
The "risk vs. reward" of the invasive IPSS should be less common in cases that are otherwise basically straight forward.	25.84%	46	14.61%	26	59.55%	106
I frequently speak with a therapist.	25.28%	45	65.73%	117	8.99%	16
I am curious about service and emotional support animals and how to get one.	25.28%	45	57.87%	103	16.85%	30
I had no problem with my IPSS.	24.72%	44	16.29%	29	58.99%	105
I am in online patient forums and appreciate the resource but feel uneasy about new patients being influenced to use or not use specific treatments or providers.	24.72%	44	39.89%	71	35.39%	63
I have been very hard on myself because I believe my lifestyle choices somehow led me to this diagnosis	22.47%	40	71.91%	128	5.62%	10
I recognize that I have no real idea how to incorporate a healthy diet into my life after having bad habits for years (NO SHAME).	21.91%	39	59.55%	106	18.54%	33
I was told to call my primary care provider after surgery for things they then said they did not feel qualified to treat because Cushing's was "beyond their pay grade".	21.35%	38	54.49%	97	24.16%	43
"LESS THAN A QUARTER"						
I was offered excellent, detailed information about how to manage AI.	19.66%	35	61.80%	110	18.54%	33
I struggle with my medication dosing or compliance.	19.66%	35	53.37%	95	26.97%	48
I have attended a support group specifically for Cushing's.	19.10%	34	75.28%	134	5.62%	10
I suffered trying to find a balance with diabetes insipidus.	19.10%	34	25.84%	46	55.06%	98
I wish my IPSS had been explained in much more detail.	17.42%	31	24.16%	43	58.43%	104
I use CBD for medicinal effect / relief of symptoms.	15.73%	28	70.22%	125	14.04%	25
I would like to speak with a therapist but I experience stigma barriers.	14.61%	26	65.17%	116	20.22%	36
My IPSS experience was horrible.	14.04%	25	26.97%	48	58.99%	105
I adopted anorexic and/or bulimic behavior when my weight continued to rise without any explanation.	14.04%	25	66.85%	119	19.10%	34

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("LESS THAN A QUARTER", CONTINUED)	<u>YES / I agree / I experienced</u>		<u>NO / I don't agree / I didn't experience</u>		<u>N/A / didn't affect me</u>	
I'm worried my marriage will end because of this experience.	13.48%	24	46.63%	83	39.89%	71
I believe my marriage ended because of Cushing's.	12.92%	23	26.97%	48	60.11%	107
This experience has negatively affected my faith in my God/religion/greater power.	12.36%	22	65.17%	116	22.47%	40
I use marijuana/THC for medicinal effect / relief of symptoms.	12.36%	22	73.03%	130	14.61%	26
I take OTC or chiropractor-provided adrenal and/or cortisol support supplement(s).	11.24%	20	70.79%	126	17.98%	32
I have been diagnosed with PTSD.	10.67%	19	74.16%	132	15.17%	27
I have suspected or been diagnosed with Postural Orthostatic Tachycardia Syndrome (POTS)	8.99%	16	60.11%	107	30.90%	55

TIME TO DIAGNOSIS	
30.34%	54 TWO OR LESS YEARS
24.72%	44 TWO TO FIVE YEARS
33.71%	60 FIVE TO TEN YEARS
11.24%	20 MORE THAN TEN YEARS