Cushing's Support & Research Foundation

cushing's newsletter

Join CSRF and Adrenal Insufficiency United in Portland, Oregon
March 30 – April 1, 2023

INSIDE THE ISSUE

2022 the year in review

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https://www.facebook.com/CSRF.net/

Dear Readers:

The past 12 months have been busy and at times challenging, but the work we have accomplished together has laid a foundation for programs, events, and activities for years to come.

Some priorities for 2023 include:

- Building a first-of-its-kind Cushing's Patient Registry and supplemental programs to ensure that everyone who wishes to be a part of our mission can do so. When we collaborate together then translate our findings into the language and format recognized by the medical community, we can transform our experiences into a tool that has tremendous impact. In-depth quality of life studies that address our complex long-term unmet needs simply do not exist yet, and we're here to change that. In conjunction with the Registry, we will also create a private forum for verified enrollees of the Registry to discuss their journey with other verified patients.
- Continuing and expanding face-to-face meeting and advocacy opportunities for our members through our monthly Zoom support calls, activation and growth of our Patient Advisory Committee and more. Our biggest event will also be taking place in late March – an international Patient Conference, co-hosted this year with Adrenal Insufficiency United, in Portland, Oregon. Additional details in this issue.
- Gathering a team of motivated members to meet all the opportunities that come our way. Do you have some free time, skills and knowledge that can directly benefit CSRF's mission, and work well independently? Please reach out! More about specific volunteer jobs we're hoping to fill in this issue.
- Promoting relevant endocrine news as we receive it from the professional endocrine societies and a rolling schedule of third party opportunities from our partners and affiliates (example Global Genes, National Organization for Rare Disorders – NORD, and World Alliance of Pituitary Organizations – WAPO). There is unprecedented interest in "patient voice" and rare disease advocacy and legislation right now, and we will share many opportunities throughout the year that welcome participation from rare disease patients.
- Exhibiting at two new professional conferences. We identified that our membership is nearly unanimous that other specialties and types of doctors need to know about Cushing's, so we are pleased to announce that we will be first-time exhibitors and attendees at the Pediatric Academic Societies meeting in Washington, DC in April and the American College of Obstetricians and Gynecologists meeting the following month in Baltimore, MD. We will add others in the future.

As this year comes to a close, I look back and feel grateful for the conversations I have had with so many of you. Even the hard ones! This disease burdens us with emotional upset, physical detriment, social alienation, depression, involuntarily loss of bodily autonomy and career identity, and ongoing problems long after "cure" or "remission". I am not immune to any of this and still have significant issues myself, with several new ones as of this year, even 10 years after my first surgery. I downplay my illnesses, pains, weird veins, wonky knee, occasional word salad, and brain fog as much as I can to everyone else, but this community of patients just GETS IT. I have been given the gift of safety to be vulnerable and honest. I have been honored to be trusted with truths that have not been told to anyone else. I want very much to facilitate this personal sense of freedom to own the journey….for everyone who needs it. The Registry and other programs we're pursuing are vehicles to validate what we hide and suffer in silence, so that we can change the story for others and ourselves in the process.

It has been an honor for me to represent our community these past nine years, and we are optimistic and excited about the future of care for Cushing's patients. I have found so much validation of my own journey with Cushing's from being a part of this movement, and I can't imagine doing anything else with my time. I look forward to adding fresh perspectives in the new year.

Please reach out at any time, for any reason.

Sincerely,
Leslie Edwin
President


Leslie in Milan, May 2022, for ECE

News and Upcoming Events

Portland Conference

We are excited to announce that we will return to our conference schedule in 2023 with a multi-day meeting in Portland, Oregon co-hosted with Adrenal Insufficiency United (AIU - united4rare.org), our "sister organization" from the opposite end of the cortisol spectrum.

Dates: March 30, 31, and April 1, 2023 (the official joint welcome kicks off at 2:00pm local time on Thursday, March 30)

Location: Embassy Suites by Hilton Portland Airport, 7900 NE 82nd Ave, Portland, OR 97220

Cost: Free to attend, hotel room rate further subsidized by CSRF and AIU to a flat $150 per night if booked through us.

Registration: Begins January 9, 2023

Our agenda includes topics of interest to both groups plus separate focused sessions for Cushing's and Adrenal Insufficiency. Lunch is included Friday and Saturday, and the hotel offers free breakfast and afternoon drinks and snacks for guests.

If you've never had the opportunity to spend time with other Cushing's patients, we hope you will consider joining us for this special gathering! There will be many opportunities to network, chat, enjoy meals together, and connect in a casual social setting.

Our speakers are well-known for their Cushing's expertise and involvement in research and include:

- Dr. Richard Auchus, Endocrinologist, Ann Arbor, MI
- Dr. Juan Fernandez-Miranda, Neurosurgeon, Stanford, CA
- Dr. Maria Fleseriu, Endocrinologist, Portland, OR
- Dr. Sabrina Hickle, Neuropsychologist, Atlanta, GA

At the time of publishing this issue, both CSRF and AIU are finalizing details and look forward to releasing the complete agenda around the time of registration. Please check our website for a dedicated page for this event in early January 2023.

Hope to see you in Portland!!

Volunteer Wishlist

Do you have some free time and skills that can help CSRF grow and reach more goals? We'd love to discuss how we can partner!

For those with an interest in research, we would like to increase the summaries and articles we share. We are looking for people who have a fairly advanced understanding of medical terms related to Cushing's and endocrinology and who know how to identify relevant pieces of information in a research article that are most useful for patients.

For those who enjoy writing original content, we are looking to add a few folks to the team who can create quality of life, patient point of view, and other similar articles that will be published in our newsletters, on our website, and featured on social media.

Speaking of social media, there is huge opportunity to increase our online activity. We are hoping to find someone who has a great love for the logistics of social media, a knack for knowing what is eye-catching, and some time to help us schedule posts to ensure semi-regular, meaningful content is shared with our friends online.

Are you fluent in other languages? As we update our most common pamphlets and educational materials, we will be able to reach many more people if we are able to present these items in other tongues.

Who doesn't like data entry?! There's always data to enter. Always. If you like to plug away at a computer, can we be friends?

Do you enjoy communicating with fellow patients? Have we got a job for you! We get a lot of requests for information, someone to talk to, and help locating needed resources. We would love to have a few vetted individuals who can answer some calls or e-mails per week.

Do you have great handwriting and enjoy the ancient art of the Thank You card? We have donors, sponsors, and collaborators to thank on a regular basis, and we value the personal touch of a thoughtful handwritten note.

What are you great at that could advance our mission and improve the journey for other patients? We want to talk to you!

If you would like to discuss getting involved with CSRF, please stay tuned in January for an announcement about Patient Advisory Committee Zoom calls in 2023, or email Leslie at leslie@csrf.net for more information in the meantime. We will also have a session at the Portland conference to discuss joining the Patient Advisory Committee and using your existing skills to enhance what we do for patients.

2023 Support Group Zoom Schedule

We began a monthly support call in 2022, open to anyone who would like to join, and we are happy to continue this service in the new year. Call-in details can be accessed on the front page of our website. Mark your calendars and join us, all times listed in Eastern Time Zone:

January 14, 11:00am	July 22, 11:00am
February 8, 7:00pm	August 16, 7:00pm
March 11, 11:00am	September 9, 11:00am
April 19, 7:00pm	October 18, 7:00pm
May 13, 11:00am	November 18, 11:00am
June 7, 7:00pm	December 13, 7:00pm

CSRF Welcomes Dr. Julia Kharlip

We are thrilled to welcome Dr. Julia Kharlip, Medical Director and expert Endocrinologist at the Penn Pituitary Center in Philadelphia, PA, to our Medical Advisory Board. Dr. Kharlip has many years of experience and a research focus on perioperative care for Cushing's patients. She has great support and respect from our other Board members and is a perfect fit for our team. Thanks for joining us, Dr. Kharlip!

Want to read past issues of our newsletter? Visit our website or scan the QR code:

ARTICLE 'ESTIMATING CUMULATIVE POINT PREVALENCE OF RARE DISEASES: ANALYSIS OF THE ORPHANET DATABASE', EUROPEAN JOURNAL OF HUMAN GENETICS (2019)

300 MILLION PEOPLE WORLDWIDE

LIVING WITH A RARE DISEASE

#RAREDISEASEDAY
28 FEBRUARY 2023

RAREDISEASEDAY.ORG

Do you have a QR Code Reader on your phone or tablet?

Many articles in our newsletters contain QR codes to quickly link you to more information about the topics. If you do not already have a QR code reader on your device, there are several options in your app store.

If You Shop at Amazon....

If you shop at Amazon.com, consider shopping through Amazon Smile, which lets you donate .5% of your purchase to your charity of choice. The link to shop at Amazon and support the CSRF is:
http://smile.amazon.com/ch/04-3271267

amazon.com

Want to be on the CSRF mailing list?

If you aren't already on our mailing list, you can join through our web site at www.CSRF.net — Member Services, or just return this form to: CSRF, 4155 Lawrenceville Highway #8130 Lilburn GA 30047. **All memberships are free.**

Name

Address

City *State* *Zip*

Phone

Email

Suggested donation is $50.00 or whatever is best for you. All donations are tax-deductible. Please make checks payable to CSRF. Memberships without associated donations will receive an electronic version of the newsletter approximately one month after the print copy mails to donors. An annual donation in any amount will trigger a three-issue print subscription.

Are you a Cushing's patient?
☐ YES ☐ NO

Did you have:
☐ pituitary tumor ☐ adrenal tumor ☐ other

Would you like to discuss publishing your story in a future issue of the newsletter?
☐ YES ☐ NO

What would you like to see addressed in future issues?

CSRF Establishes A Corporate Council

Following in the footsteps of other patient advocacy non-profit organizations, CSRF established a Corporate Council over the pandemic. The charter membership period was 2021-2022, and we are honored that many of our regular sponsors have joined.

The CSRF Corporate Council is established to create regular, transparent partnership opportunities and dialogue among its members who share many common goals with CSRF:

- reducing the time to diagnosis and intensity of illness for all patients
- supporting patients and doctors with quality educational tools
- providing empathic peer support for patients
- increasing the network of providers who can diagnose Cushing's
- supporting, conducting, and participating in research to share patient-reported quality of life issues and find ways to implement measurable change based on our data and needs
- demystifying the complicated terminology and diagnostic methods involved with all versions of hypercortisolism in a way that empowers patients to understand their own journey back to health

Corporate Council members can be organizations, corporations, pharmaceutical companies, doctors' groups, philanthropists, or other entities (CSRF reserves final discretion) actively working toward real, science-proven solutions for patients' unmet and under-met needs. Though Corporate Council members do not vote on official CSRF business, we meet quarterly and are in touch regularly to discuss programs and opportunities for patients.

Our Charter Corporate Council Members for 2021-2022 and beyond are:

Corcept Therapeutics

https://www.corcept.com

Makers of Korlym and the Phase III trial study drug Relacorilant (GRACE study), Corcept was founded in 1998 and has discovered numerous proprietary molecules in their work to address unmet medical needs related to excess cortisol activity.

Scan here for Corcept's ongoing clinical trials.

HRA Pharma

https://www.hra-pharma.com

Makers of Metopirone, HRA Pharma was created in France in 1996 to provide therapeutic solutions to medical needs that had not been addressed previously by large pharmaceutical groups.

Scan here for HRA's ongoing clinical trials.

Recordati Rare Diseases Group

https://www.recordatirarediseases.com/us

Makers of Isturisa and Signifor, Recordati Rare Diseases began marketing products in 2013 to provide often overlooked orphan therapies to the underserved rare disease communities in the US. Recordati's parent company was established in 1926 and is headquartered in Milan, Italy.

Scan here for Recordati's ongoing clinical trials.

Sparrow Pharmaceuticals

https://sparrowpharma.com

Sparrow Pharmaceuticals is a fairly new company with two new Phase II clinical trials looking at their compound "SPI-62" as a treatment for ACTH-dependent and adrenal-source Cushing's. The company's goal is to develop new, targeted therapies to address unmet needs in both endocrinology and rheumatology.

Scan here for Sparrow's ongoing clinical trials.

Xeris Biopharma

https://xerispharma.com

Makers of Recorlev, Xeris Biopharma's goal is to simplify and streamline the treatment experience for rare and other patients. In addition to medication for high cortisol, they have several products in the pipeline to treat hypoglycemia.

Scan here for the Xeris opportunity pipeline.

CSRF sincerely thanks all of our Corporate Council members for their support!

A Bigger Picture Emerges When Patients Lead The Inquiry:

Examples From The Cushing's Disease and Syndrome Community

NORD BREAKTHROUGH SUMMIT, WASHINGTON DC, OCTOBER 2022

In early 2022 we formed a patient committee to discuss topics to share with international professionals at the European Congress of Endocrinology (ECE) in Milan, Italy in May. The conference organizers put an amazing spotlight on non-profit advocacy organizations this year, providing free booth space and an offer to build and lead a session on a topic of our choice. We asked Dr. Elena Valassi (Spain) to co-present on the topics of including the patient voice in research and the type of data European researchers been receiving for the last 15+ years since ERCUSYN - the European Register on Cushing's Syndrome – was launched (https://www.ercusyn.eu).

We wanted to make the case for a "supplemental" new Cushing's registry created BY patients with patient priorities leading the study. There are plenty of institutional clinical registries throughout the US – collections of data made up from the tests, treatments, and office visits of the patients who come to those locations. There is no national registry, though, and patient voice/input is extremely limited in the databases that exist now. One of our earlier encouragements came from Dr. Valassi herself, who was instrumental in the creation of ERCUSYN: she's proud of the registry and the discoveries they have made over time, but she wishes ERCUSYN had the ability to include direct patient-provided quality of life data to be a more accurate picture of the patient experience.

We feel that the time is right and that CSRF is the right group to launch this new patient-led registry in 2023, and a lot of the work we've been doing this year has been in support of that plan. Our patient committee was passionate about change and validation, and the result of our meetings was a robust report and endless talking points that highlight how much MORE we can do to support ourselves and future patients.

After ECE, the National Organization for Rare Disorders (NORD – https://rarediseases.org) announced a call for poster abstracts for their annual Breakthrough Summit in the Fall. One of the categories was "novel ways to increase patient engagement in the rare disease community" and the way we had run our committee and created our polls and report seemed like a perfect fit to share. CSRF member Sylvia Tetlow graciously offered to help analyze data from our survey and build the poster with us, and we were elated to share it with all attendees in DC this past October. This article includes the poster data. A link to the full report can be found at the end of this article.

Purpose

Cushing's Support and Research Foundation (CSRF) has discussed the impact of persistent high cortisol on long-term quality of life (QoL) throughout its nearly three decades of advocacy as a 501c3 non-profit organization. Our patient community knows they must become experts in this illness because so few providers understand the disease on a deep level. We are encouraged that the FDA and others are embracing rare patient involvement in clinical trial design, drug development, and research because our complex care needs are not fully represented in clinical datapoints alone. Dr. Harvey Cushing, this disease's namesake, famously stated that "A physician is obligated to consider more than a diseased organ, more even than the whole man — he must view the man in his world."

CSRF offers support groups, conferences, a robust website, newsletters, social media outreach, webinars, and other peer programs. In 2019 we began forming occasional focus committees to discuss unmet needs and gaps in care and understanding. We translate the content of these workshops into questionnaires that are shared with our highly motivated membership and often see response rates of 10% or more. The results and response rates of our work attract increasing interest within the professional Cushing's community, and we have collaborated with US and international doctors for comparison studies and exploration of long-term QoL topics. As a non-profit advocacy organization hyperfocused on this patient community and unburdened by institutional regulations and legal department restrictions, we are able to move fairly quickly and collect data from patients around the globe. We believe that we are perfectly positioned to launch a unique global patient registry that will compliment existing institutional registries and the European Register on Cushing's Syndrome (ERCUSYN).

Two major datasets have come out of our committee work since 2020, both largely focused on QoL topics. Initial dissemination of findings is internal, a peer celebration of validation and establishment of commonalities. We have uncovered new statistically significant datapoints to consider when talking about long-term survival and thriving despite such significant challenges.

We will continue to work toward goals that will change the landscape of care, to include:

- Validation of unreported and underreported symptoms and conditions to ensure patients are empowered, educated, and able to advocate for themselves
- Increase in partnerships and collaborations to diversify information and expand support
- Updates to existing Quality of Life and disease-specific screening questionnaires
- Support for new drug and device development
- Creation of a professional platform with IRB oversight to increase patient-provider data sharing
- Regular engagement with the medical community via exhibition, scientific posters, White Papers, and other educational and networking resources

Background

Cushing's Disease and Syndrome are caused by persistent high cortisol and can result in a multisystem breakdown that is usually not identified in time to prevent long-term damage. The many non-specific symptoms of Cushing's are fairly prevalent in the US for other reasons and likely impede swift diagnosis: weight gain, depression, high blood pressure, sudden onset pre-diabetes or worsening of existing diabetes, insomnia, joint pain…it's a long list.

Cushing's is a rare disease with a prevalence of 5-15 new cases per 1,000,000 residents in the US. Most patients are in their 30s-50s when first diagnosed. Although women account for approximately 85% of diagnoses, all patients report constant and myriad examples of gender, age, and obesity bias that affect their care.

Some rare diseases have distinctive symptoms, identified genetic mutations, and "easy" confirmatory testing; not Cushing's. The symptoms of high cortisol are shared by quite a few other conditions and onset is often gradual; this can make it difficult to see that everything is connected. Many patients report knowing something was wrong for years but being dismissed as "just needing to lose some weight and maybe see a therapist", and it is devastating that the average length of time patients report knowing they were sick before receiving a diagnosis is more than six years. Patients strongly feel that this disease is one that must become very bad before doctors will believe it. At the same time, our providers report that Cushing's Disease is the most difficult endocrine disease to diagnose.

We are encouraged by the growing number of studies that go beyond established data to introduce new concepts and deeper quality of life (QoL) understanding in the medical field. The last decade has produced several FDA approvals for drugs even with the challenge of serving a small rare patient population, and the last quarter century has seen many advancements in surgical techniques. There is a lot more to do, though. In our peer groups, we discuss these unmet needs. We form committees to identify the gaps we experience in our own care and problems that persist long after "cure". CSRF creates methods to engage membership and find our statistically significant commonalities, and then we take action. As long as patients still struggle to make informed decisions and avoid being a passive member of their own care team when faced with so many challenges before, during, and after surgery, we consider it a mandate to work toward resolutions:

- Increase access to easy-to-understand, science-supported, comprehensive information on medical, surgical, and other types of treatment options including Traditional Chinese Medicine and neuropsychological testing
- Reduce the time it takes to identify, test, and treat any form of hypercortisolism
- Increase access to expert specialists
- Reduce the overwhelming aspects of the journey and identify opportunities for better care
- Better identify misinformation to avoid making harmful choices that sometimes contribute to a delay in diagnosis
- Increase knowledge of what to expect throughout diagnosis, treatment, recovery, and beyond
- Promote individually-focused, multiple specialty management to survive cortisol withdrawal after surgery
- Better prepare for long-term quality of life issues with more and better coping tools, referrals to appropriate specialists, removal of stigma and shame, and a reclaiming of our bodies

Methods

Approximately 30 members of CSRF joined a committee for a series of Zoom workshops in early 2022 to look at QoL issues we wish to highlight when speaking with providers and researchers. Notes from these meetings were converted into a digital survey using SurveyMonkey, then approved by the committee before being sent to CSRF patient membership via e-mail (around 2000 recipients). Answers were analyzed within the survey software and converted to charts and graphs for presentation.

Data collected included demographic information (race, gender, age), disease source and current status, return-to-work behavior, autoimmune exacerbations, and 66 unique quality of life statements. 175 CSRF members completed this survey.

Results

We had a 9.1% (n=175) response rate in less than a week on a survey that took an average of 20 minutes to complete! This disease experience truly creates a desire to advocate for others, and once we start talking about things that are not yet in literature, we realize how intensely curious we are to know if other patients experienced things we did or come from similar backgrounds.

The majority of respondents (n=148) are from the US with the next most populous countries being Canada, Australia, and the UK. There were single patient respondents in seven other countries.

Racial breakdown of respondents: White/Caucasian 91% (n=159), Black/African American 7% (n=12), American Indian/Alaska Native 1% (n=2), and Asian 1% (n=2).

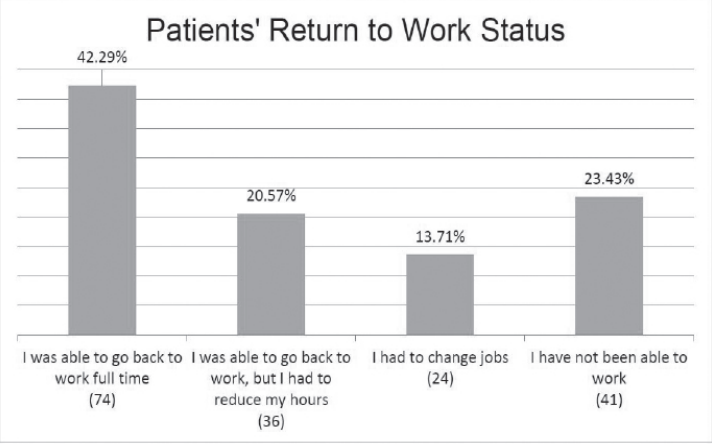
Many more women filled out the questionnaire than men: women 92% (n=161) to men 8% (n=14).

Participant age ranged from 22-88 with an average of 54 years of age.

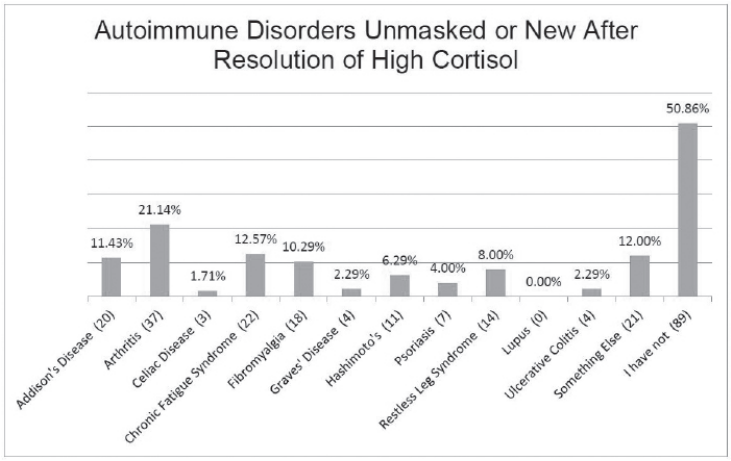
Respondents' source and status of Cushing's: 74% pituitary (n=129), 22% adrenal (n=39), 3% ectopic (n=5), and 1% unknown (n=2). 78% have had surgery and are in remission (n=136), 11.5% are experiencing recurrence (n=20), 5% had unsuccessful surgery and remain in active Cushing's (n=9), 4% have been diagnosed but not yet had surgery (n=7), and 1.5% are still seeking a diagnosis (n=3).

The bulk of the questionnaire consisted of 66 statements gleaned from the committee sessions, and respondents (n=175) were asked to choose "yes or no" if they agreed and/or that particular statement applied to them. Some examples are provided in this chart:

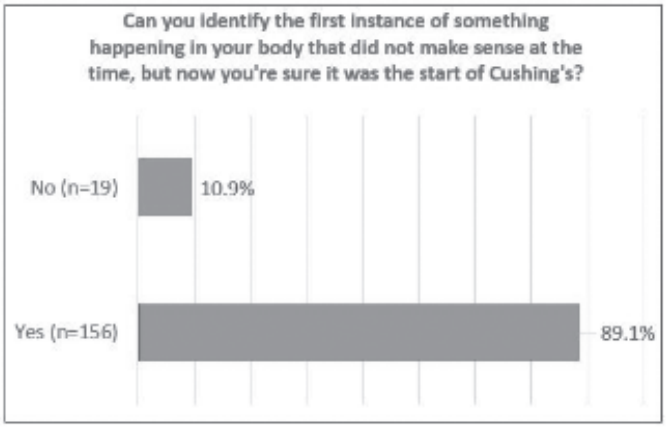
In the US, it is fairly standard to recommend planning for six weeks off from work for surgery and recovery. This is an unrealistically short window that many patients have no choice but to try to meet, often to their detriment.



Half of respondents listed one or more conditions they have to manage now as a result of Cushing's. Immune hits from prolonged high cortisol are well documented in literature.



"Half of respondents (n=87) had one or more dysregulated hormones during or after active Cushing's and required hormone replacement therapy, but only 22% of those confirmed that they felt adequately educated about the replacement."



Once we find out that the reason for our avalanche of symptoms and poor quality of life is persistent high cortisol, most of us can look back at photos or remember specific illnesses and realize that we had been suffering the effects of this illness for a long time.

PROFESSIONAL SUPPORT	Yes		No	
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
DIET AND EXERCISE	Yes		No	
I tried extreme diet or exercise to keep the weight off while in active Cushing's	65.71%	115	34.29%	60
PHYSICAL PRESENTATION	Yes		No	
People did not recognize me with Cushing's.	66.29%	116	33.71%	59
I felt like I almost had a repellent, repulsive "aura" in active Cushing's.	49.14%	86	50.86%	89
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
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
POST-SURGERY	Yes		No	
Cortisol withdrawal after a successful surgery is painful and dangerous.	73.71%	129	26.29%	46
I have been diagnosed with PTSD or CPTSD as a result of my Cushing's.	9.71%	17	90.29%	158

I have not been diagnosed, but I believe I have PTSD or CPTSD from Cushing's.	35.43%	62	64.57%	113
I have been diagnosed with new ADD / ADHD after Cushing's.	7.43%	13	92.57%	162
Healing is a slow process and does not only include normalization of cortisol.	96.57%	169	3.43%	6
I have recovered back to pretty much my "old normal".	29.14%	51	70.86%	124
"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
HARM AND BIAS	Yes		No	
I was told I would be all better and back to work about 6 weeks after surgery.	44.00%	77	56.00%	98
I experienced humiliation and/or rejection from people I knew while I was in active Cushing's.	56.57%	99	43.43%	76
I experienced fat shaming or bias in my quest for diagnosis.	58.86%	103	41.14%	72
I experienced gender bias in my quest for diagnosis.	20.57%	36	79.43%	139
PERSONAL OBSERVATIONS AND OPINIONS	Yes		No	
This is a disease where you must get very sick before it can be diagnosed and treated.	90.29%	158	9.71%	17
"Cured" is a dangerous word.	73.71%	129	26.29%	46
Validating the patient experience is one of the most important things my doctors can do.	96.00%	168	4.00%	7
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
I believe it is important to educate primary care providers about this condition.	99.43%	174	0.57%	1
I believe it is important to educate obesity doctors about this condition.	100.00 %	175	0.00%	0
I believe it is important to educate gynecologists about this condition.	98.29%	172	1.71%	3
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
PEER-TO-PEER ADVICE	Yes		No	
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
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
CHALLENGES	Yes		No	
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
I had to fight my insurance company on one or more treatments I needed for Cushing's.	24.57%	43	75.43%	132

I believe that all the various names for high cortisol lead to misinterpretation, self-diagnosis, and confusion.	60.57%	106	39.43%	69
I feel that my health problems are all-consuming.	52.57%	92	47.43%	83
I consider myself hypervigilant for any new sign of illness or return of high cortisol.	75.43%	132	24.57%	43
I have ongoing pain.	52.00%	91	48.00%	84
I have ongoing problems with stamina.	76.00%	133	24.00%	42
I have long-term memory problems.	65.14%	114	34.86%	61
I still find so many things stressful, and it is difficult to cope.	52.57%	92	47.43%	83

Conclusion

The success, relative ease, and appropriateness of this type of data collection by a patient advocacy group supports plans for a future registry. Our findings inspire patients to become more proactive in their own care. Shared best practices offer new considerations for patients with similar quality of life issues. Patient-Provider communication is improved when the patient is educated and empowered with science-backed, factual data and encouraged to be their own vocal advocate. The value of an active patient advocacy group is further solidified for all stakeholders when the patients' lives improve as a direct result of their involvement with the organization.

To view the data from the 2020 Patient Quality of Life Survey, please visit https://csrf.net/wp-content/uploads/2020/12/PDF-SURVEY-DATA-for-newsletter.pdf or scan the QR code:

SCAN ME

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2022 UPDATE AND A DEEPER DIVE INTO QUALITY OF LIFE (QoL) TOPICS: A SURVEY OF 175 CUSHING'S PATIENTS, CSRF

To view the full 2022 report, visit https://csrf.net/wp-content/uploads/2022/08/CSRF-QoL-2022-Report.pdf or scan the QR code.

Rainbow Shines on Rare:

Cushing's community poised to benefit from expanding research focus on inequities in access to rare disease diagnosis and care

William Looney

A common thread in the treatment experience of Cushing's patients is discovering how little mainstream medicine understands about the condition. Even compared to other rare diseases, diagnosis of Cushing's is slow. Its characteristic symptoms are often mistaken for more common ailments or lifestyle behaviors that can resolve without specialized medical intervention. A recent meta-analysis from clinical records of over 5,000 Cushing's patients found the mean time from first symptoms to an accurate diagnosis was nearly three years, a lag that the study authors concluded was excessive and needed to be improved.

The question, though, is how? While science continues to make progress in identifying heritability and the complex biologic interactions behind uncontrolled hypercortisolism in humans, much less is known about the many non-medical factors that influence the treatment that Cushing's patients actually receive. The impact of these so-called "social determinants of health" has been hard to quantify using standard statistical measures.

Nevertheless, there is a growing consensus in the rare disease community that something as simple as a patient's zip code may explain the persistence of sharp variations in individual outcomes from disease. Such disparities in diagnosis and access to care are especially prevalent in the Cushing's patient population even though a clinically validated practice guideline covering care for both the disease and its underlying condition, hypercortisolism, has been in place since 2008.

New Cohort Study on Cushing's: Are Minorities Missing Out on Modern Science?

As interest in health disparities builds among key patient advocacy groups like the National Organization for Rare Disorders (NORD), a number of small-scale research studies are investigating whether implicit barriers to access and treatment can affect outcomes and overall quality of life for patients with Cushing's. A recent edition of the Journal of the Endocrine Society features a retrospective study on the effect racial identity has on presentation and post-operative outcomes in African-American and white adults with Acromegaly (ACM – another rare disease caused by a pituitary tumor) and Cushing's Disease. The authors cite their work as "the first report that underlines significant differences in clinical and biochemical presentation between African-American and white patients with ACM."

The research analyzed the pre- and post-operative course of 241 male and female patients from the metropolitan Atlanta area who received standard-of-care transsphenoidal surgery (TSS) treatment at the Emory University Pituitary Center, a leading, high case-volume academic medical facility.

Key findings from the study are as follows:

- Despite having an equivalent proximity to Emory's Pituitary Center, black patients with ACM were less likely to undergo TSS treatment than white patients. The ratio increased when household income and medical insurance were taken into account. Together

with differences involving clinical and biomedical presentation, which may be attributable to later diagnosis of ACM among black patients, the study finds a significant underrepresentation of black ACM patients in TSS operative care treatment at this world-class center for surgical pituitary interventions.

• With respect to the study cohort with Cushing's, no major racial disparities were identified, but the peak age for TSS was 10 years later for African-Americans than for whites, and a comparatively small number of black patients at Emory were diagnosed with Cushing's after age 50.

• Policy-related remedial measures to address these imbalances should include patient education outreach and targeted health delivery measures aimed at shortening the diagnostic delay for blacks, such as increasing minority population access to referral centers. Intermediating issues like access to public transportation and level of education remain to be explored.

• Larger studies are required to confirm the race impact on treatment access and outcomes involving patients with ACM and Cushing's Disease. Work here could be assisted by the development of disease-specific regional and national data registries.

Other recently published peer-review studies have confirmed a discrepancy between white people and Hispanic and African-American populations in the severity of Cushing's; again, this is largely due to the white cohort's experience of earlier diagnosis as well as better ability to access facilities with expertise in neuroendocrine interventions. An August 2017 study looking at 129 pediatric Cushing's Disease patients age 18 or younger, divided between non-Hispanic white and Hispanic/African-Americans, found a disproportionately higher severity of Cushing's in the latter, at both the pre-operative (later diagnosis) and post-operative stages (a threefold higher risk of recurrence of Cushing's after TSS surgery).

Specifically, it cited a higher prevalence of obesity among Hispanic and African-American children as one factor explaining the severity of Cushing's in this group compared to whites. The rationale was that clinicians were less likely to single out obesity as a presenting symptom of Cushing's, further delaying time to diagnosis. Instead, it was usually attributed to the lifestyle and cultural behaviors present in low-income communities where many of the Hispanic/African-American survey population live.

Because early diagnosis and treatment can mitigate the severity of disease, Cushing's patients stand to benefit from researchers' increased attention to disparities in access. There is also movement on the policy front to promote health equity and outreach involving affected populations. In 2021, the National Institutes of Health (NIH) announced a new grant program, Transformative Research to Address Health Disparities and Advance Health Equity, to expand financing for study projects focused on minority-serving institutions and the ways that community barriers to access can be addressed and resolved.

Likewise, the federal Centers for Disease Control and Prevention (CDC) recently adopted a Health Equity Science and Intervention Strategy that elevates health disparities as a core priority for the organization, with a shift from simply documenting their existence to actions involving the design, implementation, and evaluation of its entire research, data, surveillance, and disease intervention capabilities.

NORD's New Message to Members: Share Your Colors

But perhaps the most important development in this space is the embrace of the disparities agenda by the National Organization for Rare Disorders (NORD), representing 260 advocacy groups working for 30 million rare disease patients across the US. NORD, which has a Patient Assistance Program (PAP) covering drugs and related treatments for Cushing's Syndrome, made health disparities the theme of this year's 25th annual Rare Disease Day on February 28, 2022.

The theme "Share your Colors" (https://rarediseaseday.org) set the tone for NORD's public advocacy in 2022. They incorporated high-profile events, encounters with political and social leaders, shared personal stories on social media, and promotion of a diversity-focused research agenda spotlighting inequities in access and treatment for minorities based on race, gender, age, income, urban/rural status as well as other underrepresented communities.

NORD is now supported by the new Rare Disease Diversity Coalition (RDDC*), launched in February 2021 on a campaign to prioritize rare diseases in a more global and inclusive way, attracting support from professional associations and trade groups. Said a spokesman for RDDC, "no patient should face health disparities, particularly those fighting the burdens of a rare disease. The communities we serve are diverse and some of them face challenges in accessing a diagnosis, specialty care, or the treatments they need. We are determined to change that."

As the chief advocate for patients with Cushing's, CSRF will continue follow the emerging research and policy agenda on rare disease disparities as it unfolds.

*The RDDC was spearheaded by the early grassroots work of the Black Women's Health Imperative, founded in 1983 in Atlanta as the first non-profit created to help advance the health and well-being of 22 million black women and girls in the US. Other members of the RDDC include the American Medical Association, the federal Patient Centered Outcomes Research Institute (PCORI), the National Hispanic Medical Association, and Retrophin Inc.

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Q I'm in recurrence and my doctor put me on fluconazole to control my high cortisol instead of ketoconazole because he said it's safer. It seems to be working fine but I haven't been able to find anyone else who has taken it to compare notes. Is there anything I should be concerned about taking fluconazole to control high cortisol?

A Fluconazole can also cause liver inflammation, rarely severe hepatitis. I don't think that there is good evidence that it is really safer than ketoconazole. Monitoring of liver chemistries is needed on fluconazole therapy and the patient needs to be warned about the risk of hepatitis (which can be rarely life-threatening). (Dr. Nicholas Tritos, Mass General, MA)

A The experience with fluconazole in treatment of Cushing's syndrome is limited to case reports in patients who also had fungal opportunistic infections or experienced intolerance to ketoconazole. Therefore, its safety and efficacy were not sufficiently evaluated. Also, a comparison with ketoconazole or other medications evaluated in clinical trials cannot be done. While availability of different medications differs from country to country, the updated Pituitary Society consensus guidelines for Cushing's disease were published late last year and illustrate the current knowledge regarding the medical treatment. (Dr. Adriana Ioachimescu, Emory University Hospital, GA)

A I can provide limited experience having controlled one patient with persistent Cushing's disease with fluconazole during several months until more definitive therapy.

It is correct that no large studies have been conducted with this drug and will probably never be. However in vitro studies conducted by well recognised expert investigators in Rotterdam clearly demonstrated its efficiency as a steroidogenesis inhibitor and it was shown to be effective in several case reports mentioned in that article demonstrating its activity.

One potential advantage of fluconazole would be that in contrast to ketoconazole it does not require an acid stomach for its absorption. The patient in whom I used it could not discontinue her proton pump inhibitors for reflux gastritis and we switched her to fluconazole with success. Clearly it will remain away from guidelines recommendations because of lack of any systematic prospective or retrospective studies. However many patients with CS are on proton pump inhibitors and this potential use of fluconazole may be of benefit in some of them. (Dr. Andre Lacroix, CHUM, Canada)

Q I read that melatonin is regulated by the pineal gland, and wondered if there is a connection to the insomnia that we experience with Cushing's. I never see anything about the pineal gland in research, but everyone knows melatonin supplements help you sleep.

A Insomnia in Cushing's syndrome is thought to be caused by the perturbation of the circadian rhythm of cortisol secretion with high levels at bedtime. Of note, other factors can affect sleep duration and quality including sleep apnea, anxiety and depression. These should be carefully evaluated prior to making therapeutic recommendations. Old studies in small numbers of patients yielded contradictory results regarding effects of high cortisol levels on melatonin secretion. (Dr. Adriana Ioachimescu, Emory University Hospital, GA)

A There isn't much on melatonin in Cushing's, but melatonin circadian phase didn't seem to be affected in one study. A study of shift workers suggested that melatonin can help re-set the abnormal circadian pattern but whether that relates to the increased cortisol was not evaluated. In my experience, some patients (usually the ones with milder insomnia) improve with 3 – 10 mg melatonin, but I also prescribe sleep hygiene changes (dark room, no screens for 2 hours before bed or in bedroom, no food or exercise within two hours, no reading in bed, consistent bed time, warm bath, warm milk (tryptophan)), so I don't know if it is the melatonin or something else. I'm sharing a nice summary of circadian issues. (Dr. Lynnette Nieman, NIH, MD) Editor's Note: Scan the QR code or visit this link to view the paper: https://csrf.net/wp-content/uploads/2022/12/Circadian-Rhythm.pdf

Q I read about a new type of surgery for tumors that are in the cavernous sinus, that involves going through the medial wall to access the tumor instead of the traditional way. Are there statistics on how often a pituitary tumor ends up in the cavernous sinus?

A With respect to direct surgical approaches to the cavernous sinus, there are numerous publications about a more direct approach to the cavernous sinus through the maxillary sinus rather than trans-nasally. However, there is no data of which I am aware that defines a better rate of "endocrine cure" using that approach for tumors invading the cavernous sinus, and there is less access to the sella via the trans-maxillary approach. Trans-nasal surgery with endoscopic visualization of the cavernous sinus remains the standard for these procedures since these tumors arise primarily within the sella and may then invade the cavernous sinus as they grow. (Dr. Martin Weiss, USC, LA)

A Yes, the cavernous sinus can be accessed through the medial wall by an endonasal approach. The statistics on the incidence of pituitary tumor extension into the cavernous sinus varies by type, for example, it would be a rather common finding in growth hormone-

secreting adenomas at the time of diagnosis; and a rather uncommon finding in Cushing's.

As with any operation, not "just any" neurosurgeon can perform this type surgery – it should be the province of those that are trained to do so and have the experience and outcomes that it is safe and effective for patients. (Dr. Nelson Oyesiku, UNC Chapel Hill, NC)

A Removal of the medial wall of the cavernous sinus is not a new surgical procedure. It has only gotten more attention recently because of some new articles on the subject, but it has been described and practiced for over 15 years by specialists in pituitary surgery. I also agree that only specialists in this type of operation should undertake these types of surgeries and that most neurosurgeons will not be comfortable performing it. (Dr. Theodore Schwartz, Weill Cornell, NY)

A Regarding statistics, my favorite paper on this topic is by Dr. Ed Oldfield, published in 2002, on his series of 68 patients with recurrent ACTH producing pituitary adenomas. 3/68 (4.4%) had dural invasion at the initial surgery, but 42/68 (62%) had dural invasion at repeat surgery. Dural invasion is clearly a problem. There are many dural folds which surround the pituitary gland and create the cavernous sinus. Removal of the dura of the medial wall of the cavernous sinus can be dangerous due to the important neurovascular structures nearby, which is why, as Dr. Schwartz mentioned, only specialists should be performing that procedure. (Dr. Michael Catalino, UNC Chapel Hill, NC)

Q I've read that the longer you have high cortisol, the worse your long-term health will be. I've also read that most patients feel that Cushing's is something that has to get bad before anyone will diagnose it. I asked my PCP at my last annual exam to add cortisol to my labwork because I have a few symptoms that lead to Cushing's in a google search. She raised her eyebrow but agreed to it. My 8am serum number was two points below the upper limit but she said that's not high. I can't help but wonder if maybe it's just not high enough yet? How are normal ranges for cortisol determined, and why are they different at different labs? Is it ever recommended to test cortisol annually with other labwork?

A An AM serum cortisol is the least valuable test to evaluate the presence of Cushing's Disease or any other form of hypercortisolemia. If one looks to limit your evaluation to a measure serum cortisol, you need to measure both AM and PM cortisol to evaluate the normal diurnal variation of serum cortisol. On the other hand, the gold standard remains a 24 hour Urinary Free Cortisol for evaluation of excess cortisol secretion. Many people have symptoms suggestive of hypercortisolemia; the diagnosis depends upon careful laboratory evaluation. Most labs have standardized protocols to guide their assessments; the values for Urinary Free Cortisol are fairly standard across the board. (Dr. Martin Weiss, USC, LA)

A Measuring morning serum cortisol is generally of no use in the diagnosis of Cushing's syndrome and is not recommended. Late night salivary cortisol, 24 hour urine free cortisol and dexamethasone suppression tests can be used for diagnosis. If you and your primary care physician are concerned about the possibility of Cushing's syndrome, please request a referral to an endocrinologist for further testing. (Dr. Nicholas Tritos, Mass General, MA)

A You are right in that prolonged exposure to high cortisol levels can be detrimental to long-term health. Normal ranges for cortisol can also vary depending on the time of the day, medications taken and the clinical context, and varies between laboratories because of different methodologies used to analyze different specimens. Normal ranges are often determined from a group of normal healthy individuals. Testing cortisol annually with other labwork should only be done based on the clinical context of the patient. (Dr. Kevin Yuen, Barrow Neurological, AZ)

Q Is medication an option to try to lower cortisol if my testing is inconsistent but has some highs, and I think my symptoms are because of high cortisol? Things like weight gain, acne, buffalo hump, high blood pressure, now I'm pre-diabetic, etc. Nothing shows up on scans yet but I've heard there are some medications to lower cortisol and I'd like to try one if I can.

A The best treatment for Cushing's syndrome is surgery to remove the tumor that causes it. Medications that decrease cortisol levels are generally recommended for patients who cannot be cured by surgery and need additional treatment (often in patients with pituitary tumors that have received radiation therapy and are waiting for its beneficial effects to occur). All medications that decrease cortisol levels can have serious side effects, including excessively low cortisol (adrenal insufficiency), and require careful and regular monitoring in consultation with a specialist. Because of their possible risks, it is not advisable to take such medications if you do not have Cushing's syndrome. I would recommend that you see an endocrinologist with expertise in Cushing's syndrome in order to help you find out if you have the condition and direct you to the best course of action regarding treatment. (Dr. Nicholas Tritos, Mass General, MA)

A Cortisol levels can rise and fall throughout the day depending on many factors. If you think you have symptoms due to high cortisol levels, then the most important thing is to do is to seek an endocrinologist who will run through your history carefully and then perform appropriate tests to determine whether you have inappropriately high cortisol levels that makes up the condition of Cushing's syndrome. Scans are usually not helpful if the diagnosis of Cushing's syndrome has not been made, and scans can sometimes be unrevealing, as it

is in your case. Once the diagnosis of Cushing's syndrome is made and the source of why high cortisol is being produced is ascertained, often surgery is considered first. If you have had surgery and still have persistent or recurrent Cushing's syndrome confirmed on biochemical testing, then usually only at this point are medications considered to lower the cortisol levels. I suggest working with an endocrinologist to determine which medication will suit you to lower the high cortisol levels. (Dr. Kevin Yuen, Barrow Neurological, AZ)

Q My local doctor refused to test my cortisol and said my problem is clearly related to obesity. I've been a little heavy throughout my life but it packed on much faster over the last year plus I have many Cushing's symptoms. I looked up at-home or self-order lab cortisol tests and they're not expensive – will an endocrinologist take the results of any of these tests seriously if I order them myself because my PCP refuses to? I have a LabCorp and Quest near me.

A Commonly used tests for the diagnosis of Cushing's syndrome include late night salivary cortisol, 24 hour urine free cortisol and dexamethasone suppression tests. Although not expensive, these tests need to be done under appropriate conditions (time, avoidance of contamination by "cortisone", etc) to ensure their validity. It would be preferable for you to see an endocrinologist and initiate testing under their care in order to clarify the situation. (Dr. Nicholas Tritos, Mass General, MA)

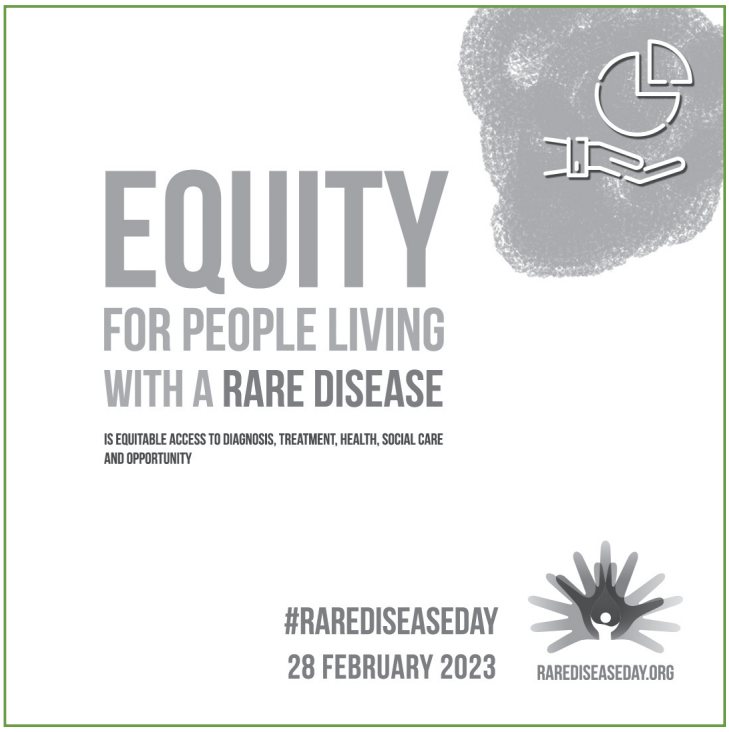
Q I have panhypopituitarism from multiple pituitary surgeries. I am a woman not yet menopausal age, so I need estrogen. However, progesterone makes me ill, and we can't take estrogen without progesterone – unless we remove our uteruses! I recently heard about two medications – Tibolone and Duavive – that provide estrogen without needing progesterone. I'm confused by what I read about them, though, and they don't appear to be available in the US anyway. Are there any estrogen options that don't require progesterone or hysterectomy? Can a US doctor help a US patient access these medications?

A Among women taking estrogen supplements, progesterone is needed in order to avoid excessive thickening of the uterine lining, which can lead to heavy vaginal bleeding or even endometrial cancer. If you cannot take progesterone by mouth, then please discuss with your gynecologist the possibility of having a progestin-releasing intrauterine device (IUD) placed (such as Mirena, Kyleena and others). This will allow you to take estrogen safely. (Dr. Nicholas Tritos, Mass General, MA)

Q What is the biggest challenge you face as an endocrinologist when diagnosing, treating, and following up long term with Cushing's patients? or What is the biggest surgical challenge you face when treating Cushing's patients?

A (Endocrinologist) Cyclic Cushing's syndrome can be particularly challenging to diagnose, often leading to delays in recognition and treatment. In addition, recurrence of pituitary tumors causing Cushing's can pose significant difficulties for the patient and their physician. Some tumors causing Cushing's syndrome cannot be fully removed for a variety of reasons (for example, because of their size or location). A team approach that includes an experienced surgeon, an endocrinologist and often a radiation oncologist is important in order to achieve the best outcomes. (Dr. Nicholas Tritos, Mass General, MA)

A (Surgeon) One of my biggest surgical challenges in Cushing's patients is identifying a tumor at surgery in a patient with a negative MRI preoperatively. (Dr. Nelson Oyesiku, UNC Chapel Hill, NC)



In Memoriam: Danielle Reszenski

It's been a year since we lost our friend and longtime volunteer Danielle to Adrenal Insufficiency. Her mother, Nan Butterfield, wrote a touching tribute to Danielle on the anniversary of her death this year. We miss Danielle every day and cherish the time we got to spend with her.

Danielle's Story

1st Anniversary of her death 9/24/22

Danielle has been gone a year now. Her passing has left such a void in my life and in her brother, sister and dad's lives. Shortly after her death, Danielle's sister announced that she was expecting a baby! A new life - certainly no replacement for the loss of Danielle, but I believe Danielle played a part in this good news… a glimmer of hope in those sad, dark days. Now, baby Sawyer is here! He's healthy and so loved. Danielle would have been the best aunt. She was a "baby whisperer".

From a very young age, Danielle lived her life in doctors' offices. As a child she had numerous strep infections, even after tonsillectomy. Her immune system was not good at all. If there was a virus out there, she caught it!

Danielle was a cheerleader in high school. She wanted to be involved and help others. In spite of terrible bullying, she graduated from high school and headed to the University of Vermont for premed. Within three weeks of freshman year she was hospitalized for pneumonia. She had numerous kidney stones throughout her four years at UVM along with a couple more bouts of pneumonia. She got to know Fletcher Allen Hospital, located on the edge of the UVM campus, as well as she knew her way around Mass General back home in Massachusetts. Danielle gained extreme amounts of weight during college and sought the help of several neuroendocrinologists. Each and every one of them told her to go on a diet and take antidepressants. We finally found a gynecologist who requested an MRI. That's when her pituitary tumor was discovered.

A debilitating and excruciatingly painful 14 years went by with so many doctors' visits and hospital stays, too many to count! Throughout it all, Danielle tried to remain positive and educate herself and others on her rare diseases. She was an active member of CRSF and Adrenal Insufficiency groups.

Barcelona was a dream trip for her and we managed to get over there right before Covid. It was a trip of a lifetime and the last trip of her lifetime. She fostered a newborn baby, with my help, until her death. She had the experience of being a mom, one of her biggest wishes was fulfilled! An adrenal crisis took her life. Her body could not take any more stress and her heart just stopped.

Danielle only lived 35 years but her accomplishments and her extreme kindness and goodwill were enough to last a long lifetime! She is missed by family members and friends as well as colleagues.

Danielle, you are finally free of pain and suffering. That is my only comfort.

Everyone who knew Danielle knew she was an advocate – she never passed up an opportunity to educate others about Cushing's and Adrenal Insufficiency. After her passing, her family directed gifts in her name to CSRF, and the extremely generous recognition of Danielle's work has enabled us to establish a first-ever scholarship in her name. Stay tuned for the official announcement in 2023 on Danielle's birthday, March 26.

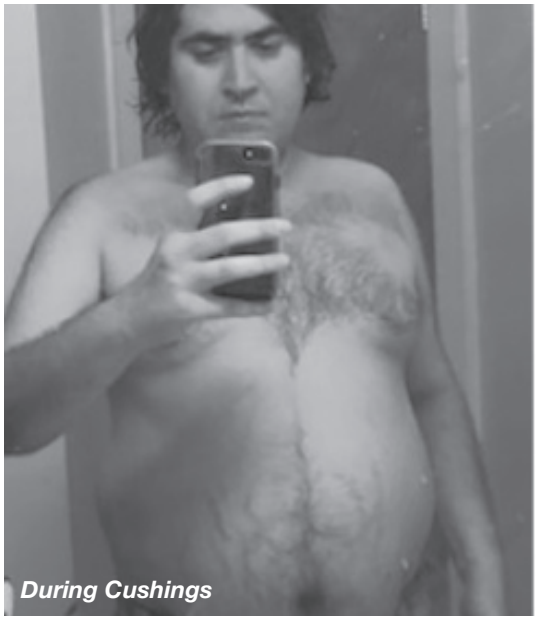
Alan's Story

Background

The story of my Cushing's Disease begins long before I knew anything about it. I really can't be sure exactly how long before, since the symptoms of Cushing's are ambiguous and there are things that I could speculatively attribute to it that go as far back as my high school years. Looking back now, however, the real start to the story is when doctors started telling me that I had high blood pressure (HBP). One reading, I was told, didn't mean anything. I was nervous, or I had too much coffee that morning. It wasn't just one reading though. It seemed to happen every time, and with whichever doctor I happened to see. Whether it was a yearly physical, one of my bi-yearly checkups with Dr. Vivian Sobel, the endocrinologist managing my adolescent bout with thyroid cancer, or even the dermatologists I was seeing at the time to deal with a stubborn case of warts. Every time the number would be high, the doctors would express some mixture of surprise, confusion, and concern, and I would be left wondering if I was doing something wrong when it came to my health.

Everyone seemed to have an opinion about what was causing the HBP. Some thought that it might be some latent symptom of my thyroid medication made manifest, but I had been on the same dose for over 10 years at that point, and Dr. Sobel assured me that it was an unlikely explanation. Others, including Dr. Sobel herself at the time, thought that it was because I was a bit overweight. That however didn't feel quite right as an explanation either, since I was already around the same weight before the HBP problems, and the first high reading came after a period when I had actually just lost about 10 pounds. So my confusion about my own condition continued.

After a year or two of that I was finally prescribed my first blood pressure medication. It was around 2017; I was 24 years old, and my doctors all thought it was strange that we had to resort to that at my age, but the numbers were so alarmingly and persistently high that it seemed we had no choice. It took years, however, before we figured out what really worked. I started off with lisinopril, but I had a bad reaction to it that affected my singing (I am an opera singer) so we quickly changed to amlodipine. That helped some, but the number was still consistently high. After a while we added hydrochlorothiazide, because I was told that a water pill in combination with the other medication sometimes worked better. Which it did, but still not completely. It was only a few years later that we added the third pill, propranolol, to my daily pill regimen, and only then were we able to get my readings down to normal levels. I actually took a picture of my home blood pressure monitor the first time it read 120/80, quite close to when I first started the propranolol. I finally felt like I had at least some control over this problem. But there was still a feeling that things weren't quite figured out yet.



During Cushings

Diagnosis

In the summer of 2019, I decided I was finally going to take time out to get some things in order, including my health, and part of that summer was switching PCPs. That summer I started seeing Dr. Young Ho Han, mostly because he was the closest Board Certified doctor to where I live in Westchester, NY, but he ended up being the perfect fit for me, and he is still my PCP as I am writing this. He is humble and would deny it, but I give him a lot of credit for starting me on the path that eventually led to us discovering my Cushing's Disease. He was the one who prescribed the propanolol, but at the same time he told me that it made no sense that I should have to be on 3 blood pressure medications at my age, so he was determined to find a root cause. He ordered all kinds of tests, most of which came back normal, but one day he called me and told me that my cortisol levels were elevated, and that I should talk to my endocrinologist about it. I reached out to Dr. Sobel and she ordered some tests of her own. That process culminated in the MRI that revealed the pituitary tumor that indicated that I had Cushing's Disease.

Treatment

Unrelated circumstances led to the next stage of my story unfolding quite slowly. Dr. Sobel connected with me with her colleague Dr. Georgeanna Dobri, the pituitary specialist who has led through the whole process up to the time I'm writing and beyond. She gave me further confirmation that Cushing's was what I was dealing with. Despite the enormity of that realization, Dr. Dobri, and later on my surgeon Dr. Theodore Schwartz, the Director of Pituitary Surgery at Weill Cornell Medicine/New York Presbyterian Hospital, projected such an assurance and depth of knowledge, that I felt at ease in her hands, and I began to feel confident that everything would turn out ok, and maybe even better than ever.

The next step of the process, however, was delayed for several months because of the first waves of the COVID-19 pandemic. I got my diagnosis from Dr. Dobri on Friday February 28th 2020, and just a couple of weeks later the world shut down. It wasn't until June that I was able to do the final diagnostic test required before scheduling surgery, and so I had plenty of time to build it all up in my head. Eventually though, things calmed down enough at the hospital for what were considered "elective surgeries" like mine to be done, so on July 8th, I got my pituitary tumor taken out.

Post-Op

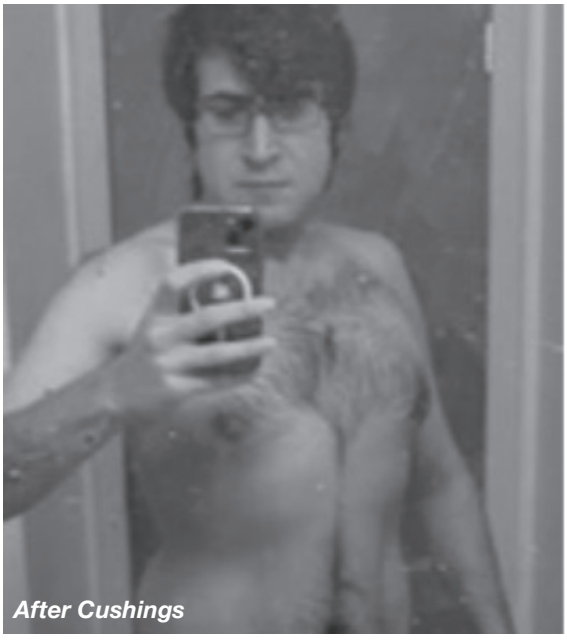
It was clear pretty quickly that things had gone well. I was told that the doctors were watching one number in particular to know that the surgery went according to plan, and it got to that level almost right away. I still had to stay in the hospital for a couple of days just to recover from the surgery, but after that I was able to go home confident that things were going to just keep getting better.

I had a few problems to deal with before I really started to feel the improvements. In the weeks after leaving the hospital, I developed a rash covering my entire torso, which the dermatologists I saw about it diagnosed as psoriasis. After a couple of years of dealing with that, and changing dermatologists, we realized that it wasn't really psoriasis but just some acute response after the surgery, and that the liger symptoms were just seborrheic dermatitis unrelated to the Cushing's. That is now under control and my skin is also better than ever.

The most obvious change was my weight. I was not very active in the months following the surgery, for both recovery and for COVID reasons, but I lost 40 pounds in the next 6 months, and almost 10 more in the 6 months after that. I've been given a reset. For years I tried through exercise and all sorts of dieting to lose weight, and it just wouldn't come off. I had a lot of shame around it and eventually just resigned myself to being overweight. It never got so out of control that I reached real obesity, so I tried to feel ok about it. Finding out that it was all because of Cushing's Disease was an incredibly validating experience.

I still don't know all of the ways that Cushing's disease affected me back when I had it. I normalized so much of it, and there are symptoms I could trace back as far back as adolescence. I'm not sure that the disease actually goes back that long, but that ambiguity is exactly what makes it hard to pinpoint exactly where the disease starts and the rest of my body's quirks end. I do know that none of the health issues I am dealing with now feel as stubborn and unyielding as the ones I was dealing with before. I also know that I have a new appreciation for the health risks of stress and I have made some significant lifestyle changes to put that realization into practice. I am told that the numbers in the regular lab work that Dr. Dobri has me do look impressively better, and I was especially interested to learn that my testosterone, which used to be notably low, is now back to normal levels. I also started a romantic relationship for the first time in nine years. I don't know if those two things are connected, but it all ties into the general upswing of my life. That relationship led recently to me getting engaged, with a plan to get married in the summer of 2024. If you had told me a few years ago that I would be where I am today, I wouldn't have believed it. It goes to show that sometimes the best things in life require one to get through the greatest struggles.

I was told by several doctors that I am a bit of a statistical anomaly. I had two, rare, completely unrelated endocrine disorders, both of which needed major surgery to treat, before I turned 30. Dr. Sobel even apologized to me for not catching the Cushing's earlier since it didn't occur to her that I could have had an issue like that on top of the thyroid cancer I had already gone through. To this day, no one has been able to tell me why I got either of those diseases, or the full extent of their effects. I still know that something else with my health could happen for seemingly no reason, if not to me, then to someone I love. Having Cushing's disease treated was one of the most positive turns my life ever took, but living through these experiences of serious disease has left me humbled. I try to remember that feeling every day, and it helps to appreciate the things that are really important. The people in my life that have helped me get through it all are chief among those things, and I will also never take my health for granted again. Never.



After Cushings

Diagnosed, Dealing & Recovering from Cushing's Disease


During Cushings


After Cushings

My Cushing's story dates back to April 2020, possibly even years before. I have always been the one who struggled with weight and of course that came with irritability, bad self-esteem, and all-around anger. I felt like no one could relate to me, and I was often told I was too sensitive and hysterical. I was in a depression for years and I thought I would never recover from it.

I decided to make some changes starting with my diet, and I started exercising too. That didn't seem to work; I was gaining weight the more I tried to lose weight. I knew something was not right with me. I was starting to show signs of purple striae on my stomach and even my breasts, but I just boiled that down to gaining weight so rapidly. I decided to go to my primary doctor and explain the symptoms I had been having.

My bloodwork indicated that my white blood cell (WBC) count was extremely high, and I was pre-diabetic. The doctor told me that I must have had a fever or been a little under the weather when I had the blood draw. At first that seemed to make sense, so she suggested getting my blood checked every 3 months. After a few follow up draws, my WBC was still elevated every time! At this point, I knew it was more than just being under the weather that caused the high count. My doctor kept dismissing it even though I kept telling her that something is seriously wrong with me! I know my body and I knew something was not right and I had to get answers right away.

I started looking into the symptoms I had and the new ones that came into my life like hyperpigmentation on all my bending parts (even my knuckles), the moon face, 70 lbs weight gain in six months. I called this my "Google" research project. I was totally miserable at this point in my life seeing the rapid change in my body. The hair on my arms were getting darker and thicker and I started to develop fatty clavicle pads to the point where I was having a hard time breathing at night while lying down. My double chin was turning into a triple chin and I just could not take it anymore!

I was tired of everyone telling me that I was not trying hard enough to lose the weight and not eating properly. They had no clue what I was going through and thought I was just a hypochondriac. Eventually in my searches I came across "Cushing's Syndrome/Disease". As I was going through the checklist, I had every symptom listed. I could not believe it! I felt like I was finally on to something.

I did research on multiple Endocrinologists and found Dr. Hamilton Fish in Leesburg, FL. After my first appointment with him, I knew that I had found my lifelong doctor. Come to find out he specializes in Cushing's and he knew right from the first appointment that I

had it. Now we had to find out if it was Cushing's Disease or Syndrome. Since he wanted me to get established in his office, he suggested I get some routine blood work done along with checking of my ACTH and cortisol levels. I had an alarmingly high ACTH level, but my cortisol was normal. He then wanted to do a few more tests to make sure 100% that I had Cushing's. He had me do a Low/High Dose Dexamethasone Suppression Test, and when I found out that he is credited with helping to determine the baselines for this test, I felt relieved, like "Wow, this guy is smart!" The results uptimately pointed to pituitary source Cushing's. So, the next test I did was a brain MRI and sure enough, I had a 6mm tumor on my pituitary! I was in shock! I had so many emotions running through my body. I was happy, sad, and relieved all at once, I did not even know that was possible!

Once I got all the testing completed, the next step was to talk about treatment and recovery. Dr. Fish brought up transsphenoidal surgery (the name alone scared me) but he went into detail about how they approach it, and it did not seem too bad. At this point with everything I had been going through in my life, I did not see it getting any worse. I was scheduled for surgery in October 2020 up at Shand's in Gainesville, Florida with a wonderful Neurosurgeon, Dr. Steven Roper. They went over the possible risks of having the surgery and the outcome of that surgery. The surgery lasted about three hours and I was told it was successful and they were able to pull the tumor out in one piece. When I woke up, the only pain I had was a sore throat! I could not believe it and even the staff as well, they thought for sure I would have actual nose and/or head pain. Don't get me wrong, I was still uncomfortable with all of the packing in my nose and all the IVs in my arms, but I guess it could have been worse. I knew there was a risk for a CSF leak and Diabetes Insipidus but fortunately, I never got either of those. After a day and a half in the ICU the staff said that my levels were where they should be, and I could be discharged! That was the best news I had heard in a long time.

I was sent home with hydrocortisone to take while I was recovering until the cells in my pituitary decided to "wake up". I was on HC for about two and a half months. The tapering process was not easy at times, but it was just one of the steps to take while recovering from this disease. Within those months, I noticed that all my brown patchy knees, elbows, armpits, and neck cleared up. My skin was brighter and softer, and the best part was that I dropped about 25 pounds in the first few weeks.

While I was recovering, I started buying all the Cushing's books I could find. I got so interested in this disease and I wanted to educate myself so I could help other people who are going through this rare and debilitating disease. This is a very scary disease, and I can see why it can take five or more years to get properly diagnosed. It carries so many symptoms that can portray other medical conditions. I used to be embarrassed about having Cushing's Disease, but you know what? It is not like I asked for it! So here is my chance to put my story out there and hopefully shed some light on this disease and help fellow Cushies. Remember, you are not alone and there are support groups out there. Do not be embarrassed or scared, we are all here to help and give support and guidance.

Rhonda's Story

My story begins in January 2019. After returning from a work trip I was laying on my back and began feeling a spinning sensation. This lasted a few days before I finally went to a walk-in clinic to have it checked out thinking it was just vertigo. My blood pressure was 152/90; they asked if I had had a bad day at work. When the clinic rechecked, my blood pressure had risen to 180/90 thirty minutes later despite doing some yoga in the exam room. Ultimately I was advised to follow up with my primary care doc, who put me on Lipitor. My BP levels remained above target even at maximum dosage. Next, my PCP added amlodipine, again not seeing the target results even at maximum dosage. She referred me to a nephrologist for my persistent hypertension because she didn't seem to know what to do with me….my case was likely too complex for her. The nephrologist didn't have any new information and offered to add Atenolol to the cocktail despite my repetitive messages of a red hot face and swollen feet.

I've been a Type 1 diabetic since the early 90s, so I made an appointment with my endocrinologist in April 2019. I mentioned the uncontrolled blood pressure issues despite being on three medications for it. I asked her to manage my hypertension. Bloodwork showed high aldosterone and low renin with an aldo/renin ratio of 25; this meant I met criteria to be screened for hyperaldosteronism. Next step in the journey was to have a CT of my adrenals, and sure enough a 9mm adenoma was identified on the left side. I then had an adrenal venous sampling procedure which showed that both adrenal glands were overproducing aldosterone.

So now, I knew why I was having hypertension. During this time the endocrinologist also had me do a dexamethasone suppression test which had a result of 1.8 – borderline for suspicion for Cushing's. At the time, the doctor called it subclinical Cushing's, but said we needed to deal with the excessive aldosterone first.

I started taking Inspra to block the aldosterone. So I had some answers and some progress....I can take medication for life, but I take insulin as well. The red hot face flushes continued daily, as did anxiety attacks out of now where, triggered by absolutely nothing. I couldn't figure out why, so I called my PCP and she prescribed Lexapro to deal with the anxiety and depression. Another answer and bit of progress, but I remained so damn tired during the day, sleeping on my lunch breaks at work, but would lay down at night and I was wide awake. Felt like I was plugged into an electrical outlet where a low voltage of electricity was vibrating in my body. I'd wake up and feel so fatigued from little to no sleep. Toss in perimenopause with hot flashes and I was a train wreck.

I noticed my breasts were getting larger, and thank goodness Amazon sells bra extenders. I began gaining weight in my abdomen, and before too long none of my pants fit around the waist. I thought maybe it COVID, or lack of exercise, because my eating hadn't changed. I never worried about what I ate before because I've been intentionally low-carb for a long time because of the diabetes. My insulin requirements increased, I gained more than 10% of my body weight in a short period of time, what even was happening?

My red face began to get irritated and splotchy with pimples.....the texture had changed. I called the dermatologist, got in same day only to be told "here is some cream, you've got Rosacea". Back to the endocrinologist in February 2021, she barely recognized me saying my physical appearance had changed so much since she'd last seen me. Finally! I needed this validation. I knew my body shape had physically


After Cushings

changed, thicker in my top half and abdomen. Sad to say but was thankful I had to wear a mask to hide how horrible my skin looked.

My doctor compared my appearance to my license photo, I didn't feel like the same person. So exhausted, working full time, dealing with primary hyperaldosteronism, type 1 diabetes, menopause, and now Cushing's was likely. I did two new dex suppression tests, and this time around I did not suppress and the results were 3.2 and 3.7. ACTH low 6s. All biochemistry pointed toward an adrenal problem. Caught some high and normal cortisol levels with saliva and 24 hour urine tests. My care team and I were in total agreement to move forward with surgery, so I had a unilateral adrenalectomy on March 8, 2021. Within a week the "veil of fatigue" had lifted, but I still had some slight headaches. They were nothing compared to weeks on end headaches experienced prior to surgery. At discharge my right adrenal gland was awake so no cortisol supplements were prescribed and I had follow-up labs scheduled for about six weeks.

Make sure you stay hydrated post op. In the months following my surgery, I took daily walks outside enjoying the sunshine. My BP stabilized. I took daily naps; it was important for me to listen to and honor my body on its healing journey. My sodium stayed low, so when I would start to feel odd, chills, palpitations, discombobulated, I would dissolve an electrolyte tab or drink Pedialyte and feel better fairly quickly.

My expectations post op surgery were high and unrealistic I think. I really didn't understand how severe the cortisol withdrawal symptoms could be, but I learned quickly. Improvements I saw fairly quickly were sleeping much better, not vibrating when I close my eyes, and not being nearly so fatigued.

Things that didn't go away as fast as I would have liked: the weight, the round face, the clothes that fit funny. My stomach remained bloated from the surgery for quite some time. Strangely, I rarely felt hungry. Every fiber in my body ached post surgery. It hurt to rub lotion on my arms and legs. Things slowly got better though.

Today, the only med I take is eplerenone (Inspra – for high blood pressure). At one point I was taking lisinopril, amlodipine, atenolol, lexapro, and Lipitor in addition to eplerenone.

I'm now almost two years post op. I practice yoga 4-5 times per week. I feel much stronger mentally. Lab results for cortisol and ACTH remain within normal levels and I even took another dexamethasone suppression test to ensure my body is working normally, and I suppressed (good news)! I can finally rest easy, sleep longer and have peace. 2023 has greatness in store for me.

Need to talk? Local support contacts and groups

Going through Cushing's is isolating, and sometimes we need to talk with someone who understands. The members listed below are support contacts in their respective cities and in some cases there are active support groups meeting. Don't see your city listed and want to discuss being a point of contact in your area? Email Leslie at leslie@csrf.net and we'll see if it's a good fit. Thank you!

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**support group*

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