Cushing's Support & Research Foundation

cushing's newsletter

2020 the year in review:

an early preview of the full issue

Slow, deep breath in…now let it out…we've reached the last day of 2020! Addressing anything about this year would be stating the obvious, so let's talk about some positive things that have happened since March.

Unprecedented research collaborations and timely info sharing on COVID / pandemic topics related to managing Cushing's and adrenal insufficiency kept us informed about how to navigate the strange tundra of ever-changing risk factors and statistics (in the beginning) and delayed or canceled treatments, surgeries, and clinical trials.

CSRF connected personally with more members than in the previous three years combined – hours spent on the phone and in e-mail that were beneficial and supportive for us, too. We were able to help 60 members with unexpected expenses when we established an emergency grant program side by side with Adrenal Insufficiency United (aiunited.org - thanks for the leadership on that, Jennifer Knapp!). We shared several research participation opportunities with patients including three in-house surveys whose results will be analyzed and disseminated in 2021 with our membership, but also within the medical community.

We had many opportunities to brainstorm outside-the-box ideas for 2021 amongst our Board and several new stakeholders and other peer organization leaders. One of the biggest announcements is that in a few weeks, we will begin the initial steps toward building the first US-based Cushing's Patient Registry! The only other similar multi-center Cushing's patient registry that exists right now is ERCUSYN – the European Register on Cushing's Syndrome (https://www.ercusyn.eu/). There are challenges to meet, but we feel that CSRF is in a prime position to

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Message From The President

administer this project. The goal is for this registry to benefit every person and entity involved with the Cushing's community, patients most of all, by combining verified clinical enrollment data with a patient input side that includes interactive modules for participants to compare datapoints to others in the registry. More to come on that soon!

Personally, I've worked from home for a few years so I did not have an adjustment in work environment. My teenage daughter is very smart and self-motivated and has taken well to digital learning. It could have been worse. I decided in Spring to take a stab at becoming a gardener and ended up loving the physical and mental exercise of clearing land and turning earth to transform tiny seeds into vining, towering, fruiting, flowering magic. My favorite time of day was between 6a-7a when the sun was up but not blazing hot yet and all the birds and bees were outside twitting about with their tiny tasks. I probably took 100 photos of squash blossoms harboring small groups of bees napping on the job, their little pollen-covered bodies buzzing back to life when I shook the stems. I had a couple of lizard buddies that would dart around the green bean trellises while I sipped my coffee and enjoyed a truly peaceful moment before the day got under way. I hope you found some successful ways to take care of yourself and your loved ones, and that the stressors and uncertainties have not weighed too heavily on you.

Thank you for being a member or friend of CSRF. We look forward to engaging even more with you in 2021.

Leslie

Me and some squash
in the morning, June 2020

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.

CSRF Welcomes New Board Member Marie Conley

Marie Conley is a consultant focusing on engagement and stakeholder strategies, fundraising development, event planning, and strategic communications through her company Conley Consulting, LLC. Throughout her career, Marie has raised millions of dollars and planned events for causes and campaigns by engaging the right stakeholders and nurtuing relationships. Today, her experience helps clients chart the right path toward aligning their activities, reinforcing their brands and meeting their goals. She also heads The Conley Cushing's Disease Fund, a rare disease-focused non-profit dedicated to supporting research on Cushing's Disease through advocacy, awareness, and fundraising.

Marie was diagnosed with Cushing's Disease in 2012. She authored her journey in her book, A Cushing's Collection: A Humorous Journey Surviving Cushing's Disease, Diabetes Insipidus, and a Bilateral Adrenalectomy. In July 2014, Marie founded The Conley Cushing's Disease Fund, fiscal sponsor TFEC. The Fund has raised tens of thousands of dollars to fund research to educate medical professionals on early diagnosis of Cushing's, and to support and coordinate a community of Cushing's patients throughout a five-state area surrounding Pennsylvania. She was instrumental in the passage of the PA Rare Disease Advisory Council in 2017 and was appointed by the Governor and legislature to serve on its board. She has also been the state coordinator for the Rare Disease Awareness Day in Pennsylvania since 2016.

Marie was unanimously granted Governor Emerita status by the Pennsylvania State System of Higher Education for her more than 13 years of service. She continues to be a guest speaker and panelist on development and stakeholder engagement for a political and non-profit organizations. She and her husband, Chris Lammando and their son, Carter, live in Elizabethtown, Pennsylvania.

The cover image, "Striped Rare," a painting by Alicia Brown was a part of Cushing's Awareness Day, 2020.

"My battle with Cushing's Disease took me through seeing myself as the rare person we all are and appreciating the beauty in nature and my surroundings."

See page 4 for more details.

Cushing's Awareness Day 2020

For Cushing's Awareness Day 2020 on April 8, we created an awareness campaign and contest soliciting written and artistic entries from members on the broad subject of their Cushing's journey. We received seven written pieces, two photographs, and three paintings, one of which graces this issue's cover. We hope you enjoy them as much as we do!

Last Day

by Bill Dodge

– a photo of his wife as they were leaving the National Institutes of Health after a harrowing treatment journey

Ambushed by Gratitude

by Bill Dodge

When we finally entered the right building on the grounds of the National Institutes of Health in Bethesda, the sight of patients and doctors from every corner of the world had an immediate impact. Seeing very sick children hooked up to medical devices and being wheeled around the hospital lobby by their families, we were reminded of how lucky we were to be where some of the best genetic research and medical care in the world was taking place. Under the guidance of Frances Collins, the NIH's inspiring director and doctor who presided over the Human Genome Project, everyone around us seemed to understand they belonged to one big human family. My rare genetic disease was just a small hiccup in the universe of the NIH.

After my voluntary participation at the hospital in a clinical study on Cushing's Syndrome, my surgeons were armed with some 2,500 test results. They were the most experienced doctors in the country at performing bilateral adrenalectomies. My pre-surgery consult was routine and straightforward. But then how much of life goes exactly as we plan? During what turned out to be a long 8-hour surgery, the surgeons discovered their laparoscopic instruments had nicked my intestines in three places. Both of my adrenal glands had been successfully removed. Cushing's had produced 12 tumors on each. But the careful inspection and repair of the intestines, which had to be done outside the abdomen, took many hours.

My immediate recovery in the ICU was complicated by repeated runs of ventricular tachycardia and a painful bloating. Three days later, after several blood transfusions to address low blood counts and my continuing discomfort, a CT exam was ordered by the ICU and revealed a large hemorrhage in my abdomen. Another tachycardia episode at the end of the exam gave the technicians some extra anxiety. The emergency had my doctors rushing in to the hospital in the middle of the night. Litres of blood had to be drained laparoscopically from my abdomen but the source of the hemoperitoneum proved hard to find, so a large general incision was made. Unfortunately, this second 8-hour surgery began with one of the scariest experiences of my life. The general anaesthetic hadn't fully kicked in when I was wheeled into the operating room. I found myself conscious on the operating table, unable to move a muscle or communicate. I was listening to the surgeons talking with each other as they began reopening the laparoscopic incisions from my first surgery. I know I was screaming at them but the screams were all in my head. I had no way of knowing how long I would be awake. Finally, the anaesthetic took hold and the longest minutes of my life were over. It's a trauma I wouldn't wish on anybody. The source of my bleeding turned out to be a small left adrenal artery. In order to get at it and clamp it, the doctors had to remove my spleen.

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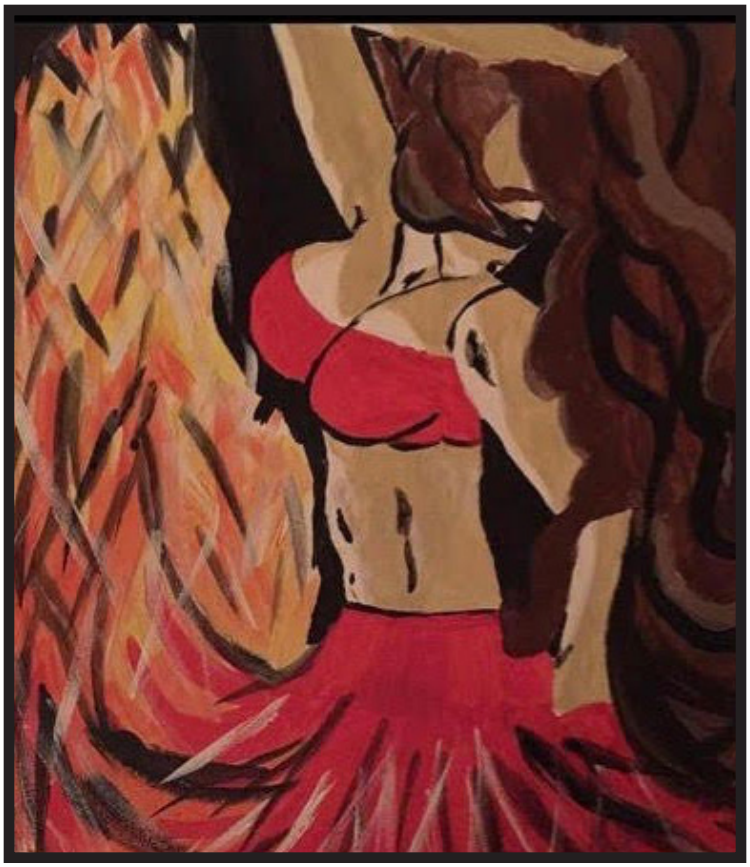
Back in the ICU, my heart was still erratic. Over the month I stayed there, I don't know how many Code Blues I experienced. At one point, one of the head cardiologists from the Walter Reed, the military hospital across the road from the NIH, was called over for a consultation. He recommended the one heart medication that finally controlled my arrhythmia.

After decades of living with excess cortisol in my body, nearly four times the regular amount, adjusting to a new biologic dose of hydrocortisone was hard. My fatigue was incredible. A social worker at the NIH had warned me that recovery would feel like coming off a heroin addiction. I could barely keep my eyes open. The room always seemed dark but I couldn't sleep. Day and night became unrecognizable. Tubes were stuck down my throat and nose at various times with some not very pleasant results. But even when I wanted it all to end, I still had an awareness of the incredible professionalism of the doctors and ICU nursing staff who were taking care of me. I had never experienced anything like this level of medical care. When the young head surgeon made a point of visiting me by himself to apologize for all the complications, his frustration and compassion were palpable. He said his team had done dozens and dozens of successful adrenalectomies. At that moment, all I wanted to tell him was how grateful I was that when things went wrong, he was there and his skill and agility made all the difference. I told him the NIH was one of the most inspiring places in the world because of doctors like him, and I meant it.

Robert Frost has a famous poem, "Acquainted With The Night," about a figure who is out in the rain and outwalks "the furthest city lights." Too often, the Cushing's experience involves a slow disintegration of emotional support. My wife and children endured a lot of changes. They had the strength to give me the time and space to rebuild and reconnect, something no Cushing's survivor can take for granted. There's a part of this experience that can't be shared with anyone, but even the smallest gestures of support can be enough to keep one getting up each morning and feeling grateful. Now the battle against the Covid-19 pandemic is shining an even more dramatic spotlight on our human vulnerability. We're all being humbled together by this. The sense of being ambushed is overwhelming, whether one's facing a rare genetic disease or a novel coronavirus. But seeing the dedication and compassion of healthcare workers from all over the globe, I can't help feeling overwhelmed by gratitude once again.



Girl on Fire

by Alicia Brown

– "Life after Cushing's has taught me to walk through the fire as if you are dancing and to appreciate the flames reconstructing our mind, body, and soul."

My New Normal

Wendy Van Camp

They say when you place a frog in cold water and slowly raise the heat, you can boil the frog alive and it won't realize that something is about to kill it because it comes on slowly. My body was boiling, but I did not perceive that this was abnormal. I thought that staying up late at night to write my novel was my choice, not due to cortisol levels keeping me awake. When I started to need a list for grocery shopping, when I never needed one in the past and that thinking itself was slower, I put it down to my age and natural processes.

Then my diabetes went haywire. I developed high blood pressure issues. The final warning that my life was boiling away was when an old friend came by and I had not a clue who she was. Later, I realized I had known this woman for many years. Every alarm bell in me went off.

Thanks to a new endocrinologist, my life was about to change.

"I believe you have Cushing's Disease." My doctor opened a book to show me pictures of people that reminded me of my old world relatives from Ukraine.

"No, my body is normal. I'm from old Russian peasant stock." How could this possibly be happening to me? It was inconceivable.

"Let's do some tests."

Saliva tests. A test for bone loss. Blood work. Urine tests. It took months. During the entire time, I did not believe I had this rare, fatal disease. Yet, the results could not be denied. I had high cortisol levels, the start of osteoporosis years too young, and my stomach was slowly turning into a distended beach ball while my legs and arms shriveled into twigs.

The final tests were MRIs of my brain. I was so large I barely fit inside the chamber and feared that I'd become stuck inside. When the test finished, the technician was very gentle and told me how brave I was. He had seen something, but didn't tell me in words. His face said it all.

My neurosurgeon showed me the results later. In the center of my skull, a tumor the size and shape of an almond had penetrated my pituitary gland and had taken over its function. It was pumping my body full of cortisol at destructive levels that would end up killing me. I would undergo two surgeries to remove the tumor and lost one-third of my pituitary gland in the process. I was warned that recovery would be brutal and would take at least two years.

I became housebound and unable to do more than sit in a chair and watch television for half a year. I had no appetite and dropped forty pounds. During my fourth month of recovery, the first miracle happened. My blood pressure went back to normal. I no longer needed medicines to regulate this condition.

Six months in, one winter morning, my photographic memory returned. My thinking process increased. I suddenly could remember conversations going back for months with the clarity as if they happened yesterday.

As a writer, I found that the creative connections were so quick that I had trouble adjusting to the speed. Solutions to story problems in my novels appeared rapidly.

One year into my recovery, my need for insulin reduced. Over a six month time period, my need for insulin was cut by over half. My liver and pancreas were healing.

My "new normal" is not perfect. I am infinitely better off than I was with this crippling disease, but not everything is what it could be. I can't push myself physically without consequences and my sense of balance is permanently affected. I keep a cane by the door if I know I will need to walk a long distance. I have also given up riding my bicycle due to my poor balance. I've made social adjustments for my improved recall and now enjoy it as an enhancement to my writing career, having the ability I was born with restored. This "frog" has managed to leap out of the pot and find a new better life.

What I Would Change If I Could

Jennifer Bacon

There would be a couple elements in my journey I would change if I could. One would be for it not to have taken so long to get a diagnosis but the most important thing I would change would be not doubting myself. I knew something wasn't right but I let others comments like "that many things can't be wrong with one person", "I think you just want to be sick", and many other comments made me doubt myself and that something wasn't really wrong physically. I don't think they were said with cruel intentions but they were cruel to the inside of me who was starting to question everything about myself. I just want to go back in time and take that girl looking for answers that was so scared, I just want to take her by the hand and encourage her and to tell her to believe in herself and to not let the comments penetrate to her heart. I have learned to believe in myself trust myself despite what others think or say. I have learned to encourage myself in the Lord just as David done in the Bible. Trying to find the encouragement from within yourself and from others just doesn't happen when you aren't even sure who you are anymore. Others' comments have made you start to question your sanity because you know you're sick but nothing can be found.

I'm blessed I have a primary care Doctor who is very caring very diligent and I remember being in her office on August 5th when she looked at me wrote down three things it could be and told me it was not anxiety and I was sick and needed to get my Doctor at Vanderbilt to refer me to an Endocrinologist there to do the test to find out which of the possible diagnoses I actually had. I remember feeling like Cushing's was the best of the three possible diagnoses – hard to believe, I know, but the others gave me little chance at living. This may sound contradictory but I do want to say in the end I actually wouldn't change anything because it has shaped me into who I am now and probably prepared me for the recovery period which can be a rough, lonely, unknown road. I had a great support system and for that I'm thankful. There was nothing anyone in my support system could have done to ease the pain of my journey because each hardship each hard step was necessary for my recovery and my journey. I want to share a little story I read after my surgery and sometime on this road of recovery that has helped me accept every single struggle every single hard time and every time I haven't been able to understand or sat and wished things went differently like I think we all have at some point.

Let me leave you with this thought when you wish you could change something about your journey:

There was a king who sat and watched a butterfly in its cocoon and waiting for it to hatch. He had waited patiently and the day came when the cocoon broke open and he watched as the fragile butterfly was struggling to try and squeeze itself through the tiny crack in the cocoon. After watching for hours he took a pair of scissors to snip a bigger hole so the butterfly could emerge. The butterfly emerged but as it sat there during its short life span it never flew and it never really moved and soon it died. What the king failed to realize was that the butterfly needed to squeeze and struggle through the crack to strengthen itself enough to fly.

Tears of Life

by Alicia Brown

"Crying is not a sign of weakness, but a sign of strength that we let out to water and nurture our own wounds, creating a new view after the tears clean the surface of the eye."

The Cage

Rebecca Maxwell

"It's like a cage, Mommy," my daughter lamented at the daily regime to keep herself healthy amidst a long-term illness. She had refused my suggestion to add yet another "to-do" item on her checklist. She tried to explain what it was like for her. I didn't understand then. I do now.

I spent ten years with undiagnosed Cushing's Syndrome. In 2017, I had an adrenalectomy to remove the attached rogue tumor pumping out excess cortisol that caused my disease. Then I entered the blindsided horror that is "recovery." Through months of trial and error, some ok days and plenty of crisis days, I found a routine that allowed me to live a "normal" life. Using my body as a guide, I tallied a list of what I had to do to stay healthy and functioning.

One morning, as I pulled the bottle of my medication from the shelf, I was filled with a frustrated rage throughout my body. I clenched my hands and jaw and made a rebellious noise I hadn't heard since my children were toddlers. The pill bottle made an echoing sound as I threw it onto the floor, pills rattling around. I was sick of it!

All the things I had to do felt like bars closing in on all sides: the strict diet, regimented sleep schedule, prescribed exercise, mandatory meditation, and the pills: vitamins, herbs, and hydrocortisone – the synthetic version of cortisol.

Although too much cortisol almost killed me during Cushing's, too little cortisol could also kill me during recovery. I needed a ballpark amount of the drug in the morning and then again in the afternoon to stay alive. But that amount oscillated due to various pop-up stresses ranging from day-to-day exercise, worrying about anything, or even the weather. Plus, my goal in recovery was to wean off the drug. I had to somehow make my one remaining adrenal gland start producing what I needed naturally. But unlike diabetes, there is no monitoring system for recovering Cushing's patients. So I would make the best guess on dosage and then deal with medical crises when I got it wrong.

For a regular person, a good diet, exercise, meditation, vitamins, and herbs might be a healthy lifestyle choice. For me, it was the only way to function while going through recovery, which could take years. And this morning, I hated it all.

I looked at my medic-alert bracelet, which I had to wear in case of an emergency, say a car accident, where I was unable to tell the crew I needed cortisol to survive. It suddenly felt heavy and binding, like a shackle around my wrist. My breathing became shallow and quick. The bracelet quickly followed the medicine's placement on the floor with a satisfying metallic clank. I felt trapped with everything I had to do.

And then I realized that I didn't. I did not have to do anything. I was an adult. I could make my own choices. In fact, I had built this cage all by myself. I was both the jailer and the prisoner.

I envisioned not taking any more pills, skipping my morning exercise and meditation, and flopping on the couch with a bowl of ice-cream for breakfast. And repeat that the next day and the next. Yes, I could do that.

No one would stop me. But there would be consequences:

- Without meditation, my anxiety would slowly creep back along with my inability to handle pain.
- Without moderate exercise, my muscles and bones would never rebuild from the Cushing's, leaving me fragile and weak and achy.
- Without the strict diet, vitamins, and herbs, my inflammation would return creating pain and the need for more cortisol.
- All that pain and anxiety would disrupt my sleep, bringing on migraines, depression and a whole bunch of crap I had been thankfully leaving behind with the Cushing's.

But that would all take some time. The time I would not have since without taking the synthetic cortisol, I would descend into a medical crisis within a day and possibly die in less than a week. If someone found me and took me to the hospital, they might not treat me correctly without that bracelet.

I took a few deep breaths, the same kind I taught my children to calm down from tantrums. It was true that I did not have to do anything, but the consequences would not just impact me, but all of my loved ones as well. What had been the point of struggling through Cushing's only to give up now?

At that moment, I chose to pick up my bracelet and medication bottle. I stepped back into that cage willingly. The bars were still there, but they were not made of iron but of love. Love for myself, my family and friends, the people I had yet to meet, and the things I had yet to do. I could live with love. I choose to.

If You Could Change One Thing….

by Catherine Matthies

I have always been interested in the written word. I was taught to read from a young age, and as a result, fell in love with words and the power they held. I could easily spend hours at the library and at one stage, was even banned from bringing any more library books home by my dad. He was convinced that I would ruin my eyes with all the time I spent reading- my head constantly stuck in a book.

He wasn't very successful. Even now, I regularly visit the library, and, quite fittingly, work in an Australian-run bookstore chain.

But in all my time spent reading, I never came across a rare disease like Cushing's. In fact, I never read anything about it, and the name was unfamiliar to me. It wasn't until I was properly diagnosed over two years ago that I started to wonder why this was the case. Okay, so I knew the disease was rare, but surely there should have been some literature available on the matter? Literature, I mean, that wasn't confined to medical journals or short personal accounts on blogs and forums.

Why had I not seen books about this in the biography sections of my local library and bookstore? Were people just not interested in publishing their stories?

Or were their stories so long and complex, they just didn't have the time or inclination to write them? I know if I had seen a personal account in book format, I would have jumped at the chance to read it. Reading the comments of other Cushing's patients on forums told me that they too would have devoured anything similar, if only to compare their experiences with those of the author.

Whch brings me to the above topic: If I had to choose one element of my journey to change, what would it be, why, and what would I do to change it?

The answer to me is simple. Recording. Journaling. Documenting.

Although I am a huge reader, I am not as consistent in keeping a record of the things that happen in my life. I don't keep a journal and any entries in my diary are impersonal- I keep record of important dates and appointments, with the occasional reminder when something needs to be done urgently.

When I look back now, I really wish I had thought to write down my thoughts and feelings on each of the things that happened during my Cushing's journey. I have recorded the dates of my tests, medication changes and surgery, but have not included any personal thoughts as to how I felt at the time.

I don't even have a record of when my journey officially began. I could say it started with my local doctor, who referred me to an endocrinologist for thyroid testing, but this might not be correct. It may have started with the diagnosis of an abnormally high blood pressure for someone my age, but who knows?

If only I had recorded everything from the beginning- or as close to the beginning as possible. If only I had instilled in myself a diarist nature, I could have written a Cushing's journey biography of the sort that I longed to read. Even as the idea crossed my mind, it was too late to do anything about it. Too much time had passed, and while some of the dates would have been relevant, my thoughts on what I went through would have been inaccurate. Poor memory is one of the symptoms of Cushing's disease, and unfortunately, I had it. I couldn't give an accurate description of my experiences if I didn't remember them properly. Besides that, everything was so new to me at the time that a lot of the test records I did keep wouldn't have passed muster for someone writing their biography. With a little bit of research, I could have probably found out what most of the tests were called, and what they revealed but I just didn't have the energy or commitment. For me, inferior petrosal sinus sampling was simply the 'groin test'.

Now, having experienced everything firsthand, I can fully understand why there are so few books available when it comes to patients living with Cushing's. If anyone else has shared the same diagnosing experiences that I have, they will know that it is a grueling process, which takes a toll both physically and mentally. Unless you have been consistently keeping a record of your daily interactions, it is unlikely you will have a complete picture to present in biographical form.

Besides the written aspect of documenting, I have found that I don't even have that many photographs of my journey. I felt so depressed about my weight gain and changed appearance that I refused to let people take photos of me during this time. My self-esteem was so low that I even had my husband edit one of our engagement party photos so that I would appear to have a thinner face.

In a world where selfies are the norm and people document every aspect of their lives, the journaling of my Cushing's journey is painfully minimal. I was living (for want of a better word) on a day-to-day basis, and in hindsight, I wish I could have documented my experiences better.

Maybe then I could have written that biography that is as rare as the disease itself.

Adirondack

by Alyssa Agee

Straddled between two transsphenoidal surgeries—one failed and a second scheduled for six weeks from now—I have pulled my mammoth body out of bed to shuffle along the trail by our home. It is one of those dog days of summer where the heat settles on you like a blanket and you pray for just the smallest breath of air. After the meager two blocks to reach the trailhead, I am panting. Rivulets of perspiration slide down my spine, pooling at the elastic band of my shorts. This was a bad idea, I think; I don't have the stamina to get back to the house, much less trek any distance on the path ahead.

I forge ahead stubbornly. It's an excruciatingly slow shuffle of one foot dragging along the sidewalk to rest just inches in front of the other. My chest is pounding, and already I feel the familiar stab of pain in my lower back. Around a gentle bend in the path a garishly bright orange adirondack chair comes into view. Thank God for public seating , I mutter under my breath. Some sound reminiscent of a beached whale escapes my lips as I collapse into the chair. I pull my cell phone out and contemplate ringing my husband to come get me. How ridiculous, I sputter. How is he going to "come get me"? With a wheelbarrow? A stretcher? Perhaps he'll just pull up on his long-tail cargo bicycle and heft my hulking frame onto the bench intended to haul our children around town. In that moment a delicate breeze rises from the river far below. I shut my eyes and actually lick my lips in appreciation.

What happens next I have no explanation for. You may discount it as the crazed ravings of a Cushing's patient whose sanity has finally snapped. No matter. If I have learned anything on this journey of delayed diagnosis, failed surgeries, and dead-end drug therapies it is this: that I don't much care anymore what you think. Your opinion is just that—yours. I can't be bothered wasting any more time or tears over it; I have bigger things to worry about. Like my own death. Or how to get out of this goddamn plastic trap they've deemed appropriate for public use. Since when is it a good idea for a seat to slant backwards at such an alarming angle?

So there I was, eyes closed, thinning tank top plastered to my sweaty body exposing every roll of fat for all the world to enjoy when I am transported to the edge of the ocean. The spray of water feels so real that I lick my lips once more, expecting the salty residue of a wave. I look down and my sausage toes are planted firmly in the cool sand. All sound seems to fade away until all I hear is my own heartbeat, an erratic thud.thud.thud in my chest. My hands move to touch my chest, and in the next moment they are slowly peeling back layers of skin: like shedding one of those skin-tight polyester/spandex blend athletic shirts after a long run.

Slowly, I lift my pumping heart out of the chest cavity, cradling it gently in both hands. Keeping it close to my body, I cock my ear to one side and listen gratefully to the steady thump as it continues miraculously to beat. I sense the source of my energy vibrating through my arms and down the length of my body. Now, even the ocean and surrounding landscape dissolves and my whole being is laser focused as light begins to emanate from the exposed organ.

In torturously slow motion I make a slight jerking motion and yank the heart away from my body. I imagine that this is how Rafiki felt as he held Simba high above the Disney version of the African savanna. The colors of the rainbow are shooting out on all sides creating a display worthy of the Northern Lights. Morgan Freeman narrates, "And here is the essence of yourself… It is all joy, passion, beauty, love. All you." Instinctively, I lift this still-beating, light-encased orb up toward the sky and offer it to an unseen force. In that moment of offering, I am nothing. I am gone. And I am everything.

The light enfolds me before rushing out to engulf all I can see. At once, that nameless expanse crashes down on me in a wave. I am drenched. My body is an empty vessel. There is no pounding heartbeat—only eerie stillness. That wave carries with it the most intoxicating scent. It reminds me of orange blossoms and vanilla and the smell of a newborn. It is heady and sensual without overwhelming.

The heart has stopped. It's been cut off from the body; illuminated, but so still . In the next moment, a mysterious force performs CPR and the smell of rich perfume pumps life back into the heart. Invisible hands cup mine and gently, firmly draw the heart back and place it inside the empty cavern of my chest.

The experience was so real—so tangible—that when my eyelids popped back open, I immediately peered down and yanked back my shirt to see if there was any evidence of a horrific tear in my chest. I think that is what resurrection feels like. I think I tasted what it means to "die to self". There was the most unfathomable sense of freedom that came with the ultimate sacrifice. My being saying, " Here: take my life. " To release—to let go, to give—brings back with it an abundance, vitality, and wholeness that is indescribable.

I am stunned. If I could have managed to get down on my knees that might have been where I ended up; but the Adirondack had other plans for me. It has been nearly five years since that August afternoon, and I have to admit that I've never had a similar experience. I still occasionally walk the same trail—with a little less shuffling, and a few pounds lighter. I am still not much closer to the picture of health I desperately want to be, but I've never forgotten the smell of the great life force that breathes in and out of all of us. When my current situation seems too much to bear, I can close my eyes and recall the lightness of being that comes when I fully let go.

I did finally manage to extract myself from the evil clutches of that carrot-colored seat and make my way home.

A Poem

by Samantha Boerst

You may think monsters aren't real
Oh but dear, here's the deal
There's a little monster you see named Cushing's
and it's inside me
One day I wish I was free and this monster would let me be
I had two monsters you see but only one was living inside me.
The other monster lived with me and was just as bad as Cushing's was to me
He belittled me and would even hit or toss things at me
Telling me I wasn't worthy to he or any human being
You see, he and Cushing's made me believe I wasn't good enough for anyone, not even me
I looked in the mirror, but only to my dismay saw a stranger looking back my way
Once a smart young vibrant lady I no longer did see
Oh god, what has this man and Cushing's done with me!
I fought and fought until I could find, a doctor who didn't think I was losing my mind.
Then one day my pituitary tumor was removed and a rush of happiness began to fill the room
I no longer felt like I was doomed
I regained my self worth to tell him enough is enough
This monster inside me was now gone and it is time for you to beat the dust
Getting away from these monsters was not easy at all. You see, I had to find it within myself to make the final call
All in all it was worth the fight that gave all my might each and every night
Because when it was all said and done I finally reached the light at the end of the tunnel that once I thought would never come

Find Someone Who Knows What This Feels Like

by Leslie Edwin

"This is my friend Terri who sat in the operating waiting room all day during my first surgery so she could be the first in my room to keep vigil for hours in case I woke up nauseous, so she could put a cold towel on my head. She also spent the night during one of my long stays and brought me good snacks, a portable bluetooth speaker, and a full-sized towel. Although our hospital experiences were not for the same thing, she knew how to ease the stress that she did understand."

Medications for Cushing's Old and New

The first line of treatment for endogenous Cushing's (caused by a tumor inside the body) is surgery to remove the tumor. More often than not, though, the patient's medical journey does not end there – about a third of pituitary patients will not have a successful first surgery, around a third of initially successful surgeries will result in recurrence within ten years, and repeat surgery has a lower efficacy rate than an initial surgery.

Questions come up when high cortisol persists – is the patient a candidate for additional surgery? Radiation? Medical therapy? Options for the latter are a somewhat recent addition to the Cushing's treatment toolbox, with the majority of research, development, and approvals happening in the last decade. Older drugs that have been "repurposed" to treat Cushing's are also available.

Medication can be considered as a "bridge" to therapy – to bring severe cortisol levels down before surgery, or in the event of a delay for any reason such as we have seen in 2020 with COVID halting most surgeries for several months. It can be used to control cortisol while slow-acting radiation works (which usually takes three or more years to begin to see biochemical control). In some cases a tumor cannot be seen in scans and the surgeon might want to wait until it becomes visible to operate. There are even some patients on long-term low-dose therapy for otherwise untreatable, moderate levels of hypercortisolism. CSRF strongly encourages thorough self-education on the topic combined with conversations with your doctor when considering taking any of these medications. The choice to use a drug, or not, is an extremely personal one. The integrity of data sources available to us vary greatly, so we cannot stress emphatically enough to always make sure your information is coming from an academic or medical source, or from a non-profit organization supported by a reputable medical advisory board.

What follows is information on each of the available medications plus several currently in development. Unfortunately, all medications are not available in all countries. Within the US, many endocrinologists are uncomfortable prescribing one or more of these drugs because they do not have experience; all of the meds require careful dose titration, regular patient monitoring for safety and effectiveness, and adequate patient instruction. All of the options can lower cortisol too much and require regular testing and follow up to assure safe use. To further complicate the matter, each drug works a little differently than the others – via mechanism of action, safety, tolerability, drug-drug interaction potential, route of administration, and how quickly it works. Most medical therapies use normalization of the 24-hour urine free cortisol (UFC) test as a measure of efficacy, so you will see that referenced here.

Data taken from the recent articles "Adrenally Directed Medical Therapies for Cushing Syndrome" by Dr. Nicholas Tritos and "Updates in the Medical Treatment of Pituitary Adenomas" by Dr. Maria Fleseriu; please see references at the end of this article.

TARGET: PITUITARY

Cabergoline (generic)

-approved for management of prolactinomas, another type of pituitary tumor that produces too much of the hormone prolactin, but used "off label" for its efficacy in mild to moderate cases of Cushing's Disease

-within 2-3 years of use, more than 75% of patients tend to become "immune" to the ACTH-decreasing effects of cabergoline

-usually used in combination with other drugs or when a patient is pregnant, since cabergoline does not appear to adversely affect the fetus based on very limited safety data available (so few patients have taken it during pregnancy, there's no significant research on this topic)

Pasireotide (Signifor, Signifor LAR – Recordati Rare Diseases)

-injectable

-both daily and long-acting versions are FDA-approved for the treatment of Cushing's Disease

-more than 2/3 of patients with macroadenomas (tumors 1cm or larger) saw at least a 20% reduction in tumor volume 2-3 years after beginning treatment with pasireotide

-can take up to two months to see effects, does not work for some patients

-more than 70% of patients see some sort of increase in blood glucose levels which could lead to a need for treatment to control new prediabetes or diabetes - this effect reverses upon discontinuation of use but should be monitored

TARGET: GLUCOCORTICOID RECEPTORS

Mifepristone (Korlym – Corcept Therapeutics)

-FDA approved for patients with diabetes or glucose intolerance and hypercortisolism

-studies show more than 85% of patients have significant improvement in glucose metabolism and blood pressure and weight reduction / normalization

-increases ACTH and cortisol in the body, so management requires doctors to monitor clinical data and patient-reported symptoms since cortisol testing is useless

-female patients must take extra precautions to prevent pregnancy and problems with endometrial thickening that can be caused by the antiprogestin properties in this medication

-a high dose of dexamethasone (2-10mg daily) should be used if a patient experiences adrenal insufficiency

-patients with macroadenomas (greater than 1cm) should be closely monitored for tumor growth

TARGET: ADRENAL

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-ketoconazole can lead to low testosterone or gynecomastia in male patients

-this medication is ideally avoided during pregnancy because it may interfere with masculinization of a male fetus

-tends to increase liver enzymes, but this is usually asymptomatic and reverses upon discontinuation of the medication; about 13% of patients have mild elevation, with more severe issues (five times upper normal limit) happening less frequently

-a very rare but severe, life-threatening inflammation of the liver has been reported in 1:10,000-15,000 patients treated with ketoconazole; the FDA requires "black box" labeling because of this potential severe adverse effect, and it is unavailable in some countries because of it

-regular monitoring of liver enzymes is advisable because of the potential for serious liver injury (as noted above)

Metyrapone (Metopirone – HRA Pharma)

-rapid onset of action – begins to take effect within a couple of hours of first dose

-licensed in many European countries but "off label" use in the US, FDA approved as an ACTH test

-effectiveness is supported by many studies including one that involved 195 patients tracked over 16 years

-does not seem to have any major drug-drug interactions

-advisable to monitor blood pressure, potassium, and testosterone while on this medication

Osilodrostat (Isturisa – Recordati Rare Diseases)

-approved for use in Cushing's in the US and seven European countries for patients with active disease after surgery and those who are not candidates for surgery

-favorable effects on weight, patient-reported quality of life, blood pressure, and blood sugar have been reported

-many drug-drug interactions exist and should be discussed with your doctor

-a drop in white cell count (asymptomatic) has been noted in some patients

-some patients have reported minor QT prolongation, but no serious arrhythmias (both related to the healthy speed of your heart beat)

-it is advised for patients taking osilodrostat to monitor and maintain healthy electrolyte levels, monitor blood pressure, have periodic electrocardiograms, avoid other medications known to cause QT prolongation, and male patients monitor testosterone

Mitotane (Lysodren – Strongbridge Biopharma)

-derivative of insecticide, chemically related to DDT

-approved for use in adrenocortical carcinoma (cancer), rarely used outside of this condition

-usually used along with surgery to help prolong survival

-there is evidence that mitotane provides some pain relief for patients who can't have surgery or whose tumor has metastasized

-is used in some countries "off label" for Cushing's

-has shown some improvements in blood pressure and blood sugar

-has slow-onset effectiveness of several weeks, so not useful in urgent situations

-adrenal insufficiency occurs frequently with long-term therapy, so cortisol replacement is usually advised

-mitotane also clears hydrocortisone quickly, so a higher than normal replacement dose would be required

-many drug-drug interactions to discuss with your doctor

-it is advisable for women who may wish to become pregnant to avoid doing so within five years of discontinuing use of mitotane

-limited patient tolerance prevents widespread use in patients with non-malignant sources of hypercortisolism

Etomidate (generic)

-intravenous, used to induce anesthesia

-"off label"use for severe hypercortisolism in acutely ill patients

-only available via IV and requires admittance to ICU

-usually used as a life-saving bridge to another treatment – usually surgery – in patients with severe Cushing's

TARGET: FUTURE APPROVAL VIA CLINICAL TRIALS

The future of more and better drug options depends on innovative researchers, adequate funding and interest in our rare disease, and patient participation in clinical trials to ensure safety and efficacy. In our Summer 2018 issue we described the design and stages of clinical trials, and it warrants a reprint here:

Trials occur in phases, or stages, based on study objectives, participants, and other factors (observational studies do not operate in phases):

- Early Phase 1: exploratory studies conducted before the traditional trials begin, involve very small doses of the drug and make no claims of therapy or diagnosis of any disease
- Phase 1: studies focused on the safety of a drug, usually conducted with healthy volunteers, main goal is to study adverse events, their frequency, and how the body breaks down and gets rid of the drug
- Phase 2: studies focused on gathering preliminary data in patients with the disease, frequently involve some patients receiving a placebo, measuring safety and adverse events still a priority
- Phase 3: studies that receive the benefit of data from the first few phases of trials and involve more participants across specific populations at different dosages, measuring safety and efficacy of the drug still a priority

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- Phase 4: trials that occur after FDA approval of the drug that continue to gather safety and effectiveness data to ensure optimal use of the drug

There are several chemicals currently in various phases of clinical trial and study – see the table for more information. You can read all the data available on a trial by searching the identifier code at clinicaltrials.gov. A few in particular deserve a spotlight:

Recorlev (Strongbridge BioPharma)

Levoketoconazole, COR-003 - clinicaltrials.gov identifier: NCT03621280

Strongbridge BioPharma is currently running an open label, third Phase III trial (OPTICS) building on the efficacy and safety data from the previous two Phase III trials on this adrenal-targeted therapy (SONICS and LOGICS). On September 8, 2020, Strongbridge issued a press release that excellent results from the first two trials have put them on track to submit a new drug application for Recorlev to the FDA in early 2021, with an expected launch of the drug in early 2022.

Relacorilant (Corcept Therapeutics)

CORT125134 - clinicaltrials.gov identifier: NCT03697109 (GRACE – pituitary) and NCT04308590 (GRADIENT – adrenal)

Corcept Therapeutics is currently running two Phase III trials (GRACE and GRADIENT) looking at the safety and efficacy of Relacorilant, a cortisol receptor blocker that does not have the antiprogestin effect of Corcept's original Cushing's drug Korlym. Phase II trials for this drug completed in late 2019, and the GRACE arm is expected to complete by end of 2021. As GRADIENT began recruiting on July 28, 2020, those results will likely take a little longer. The results of the GRACE study are expected to be the basis for a new drug application to the FDA.

Roscovitine (no associated pharmaceutical company)

Seliciclib, CYC202 - clinicaltrials.gov identifier: NCT03774446

Sponsored by Cedars Sinai Hospital in Los Angeles, CA, Dr. Shlomo Melmed and his team are continuing their long-term research into the ACTH suppression and growth and size reduction effects of Roscovitine on pituitary tumors in a Phase II trial. In 2011 this team reported on their creation of a transgenic zebrafish pituitary tumor model, which is remarkable because it is otherwise incredibly difficult to access enough healthy and diseased pituitary tissue to do significant studies.

References:

Nicholas A Tritos, Adrenally Directed Medical Therapies for Cushing Syndrome, The Journal of Clinical Endocrinology & Metabolism, dgaa778, https://doi.org/10.1210/clinem/dgaa778

Gheorghiu ML, Negreanu F, Fleseriu M. Updates in the Medical Treatment of Pituitary Adenomas. Horm Metab Res. 2020 Jan;52(1):8-24. doi: 10.1055/a-1066-4592. Epub 2019 Dec 20. PMID: 31863423.

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

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

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

What would you like to see addressed in future issues?

Q: When a patient who has not had cortisol testing yet but describes the way they feel as "adrenaline surges" or "raging cortisol", is there anything else that could be causing a symptom like this?

A: There are many conditions that can give "up and downs", "spells", flushes, anxiety and a thorough history should be taken before going on the path of evaluation for elevated cortisol or something else.

Fluctuations in the blood sugars, change in sleep, "adrenergic spells" either in the setting of dysautonomia or pheochromocytoma, carcinoid, medullary thyroid cancer, mastocytosis can give surges but most of the times it is not something as serious. (Dr. Georgiana Dobri, Cornell)

A: In general, cortisol levels are consistently increased in patients with clear-cut Cushing's syndrome. In that situation, the differences in minute to minute cortisol levels (relative to the average value) is small and we would not expect the patient to experience any symptoms as a consequence of that specific increase. Some patients experience headache when their blood pressure is very high and may characterize this as a surge. Other patients become irritable and fly off the handle when they have Cushing's syndrome, and this might be interpreted as a "rage" due to cortisol. Also, some patients with cyclic Cushing's syndrome have increased symptoms when their cortisol levels are high, compared to how they feel when the values are normal or low. Patients who experience symptoms of a "surge" "rush" or "rage" should bring this up to an experienced endocrinologist, who will consider these along with other symptoms, when evaluating whether Cushing's syndrome or some other disorder is present. (Dr. Lynnette Nieman, NIH)

A: We usually define cortisol or adrenaline abnormalities by hormone measurements outside normative ranges. The episodic symptoms described as "surges" or "raging hormones" can be caused by multiple conditions, both endocrine and non-endocrine. I would start is with an evaluation by an internist and/or a general endocrinologist. (Dr. Adriana Ioachimescu, Emory University Hospital)

Q: Can you have polycystic ovarian syndrome (PCOS) and Cushing's at the same time? Can you resolve one by treating the other?

A: Yes - PCOS is significantly influenced by the genetic makeup of the patient. The weight gain which generally occurs in patients with Cushing's will often aggravate the symptoms that women with PCOS frequently have (irregular periods, facial hair growth, acne, scalp hair loss). Conversely, weight loss, which may occur after successful treatment of Cushing's, will often help improve symptoms associated with PCOS. (Dr. Nicholas Tritos, Massachusetts General Hospital)

A: Yes, PCOS and Cushing's frequently coexist in women. Unfortunately, many patients with Cushing's are told initially that they have PCOS and thus diagnosis of Cushing's could be delayed. The opposite could be also true, PCOS can falsely induce elevation in cortisol measurements and misdiagnose a patient as having Cushing's.

Due to overlapping signs and symptoms, patients need to have a proper differential diagnosis, and if they have both diseases, treat both accordingly. In a woman with Cushing's, treatment of Cushing's might resolve symptoms and improve the features of PCOS. (Dr. Maria Fleseriu, Oregon Health and Science University)

A: The important issue is here a correct diagnosis, which would allow the physician to discern one diagnosis from the other and recommend appropriate treatment. Both conditions affect predominantly premenopausal women and can cause problems with ovulation and menstrual periods, excess face hair and acne, weight gain, high glucose, and high blood pressure. PCOS is much more prevalent and lacks some of the signature manifestations of Cushing's syndrome, such as purple stretch marks, easy bruising, muscle weakness and osteoporosis. However, the presentation varies from one case to another and sometimes the characteristic features of high cortisol are subtle. The good news here is that endocrinologists can do the tests and differentiate between the two conditions. (Dr. Adriana Ioachimescu, Emory University Hospital)

Q: I've been treating a prolactinoma for many years with cabergoline, with negligible results. I've even gone off the medication several times when it didn't even seem to be stopping the galactorrhea I've had since diagnosed. Recently I've noticed that I'm

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experiencing many symptoms that look like Cushing's. Is it medically appropriate to remove a prolactinoma if it starts to grow or cause problems?

A: Although uncommon, it is occasionally possible for some pituitary adenomas to produce both prolactin and ACTH. The endocrinologist can test for the presence of Cushing's in your case. If the tumor is producing both ACTH and prolactin, then pituitary surgery should be discussed with an experienced pituitary neurosurgeon. Some patients whose tumors produce only prolactin may also benefit from pituitary surgery, if they cannot tolerate cabergoline or bromocriptine or if the medications are not effective (for example, if the tumor grows despite adequate treatment with medication). A discussion with an experienced endocrinologist would be advised in order to discuss these options in depth. (Dr. Nicholas Tritos, Massachusetts General Hospital)

A: Prolactin elevation and galactorrhea could be multifactorial. In large tumors, prolactin elevation can be due to stalk effect and Cabergoline is not efficient in making the tumor smaller, though is resolving galactorrhea in most cases. It is important to also look at concomitant medications that can raise prolactin. Sometimes, though rarely, even a prolactinoma will not respond at all to cabergoline and patients will need surgery in these cases to resolve the hyperprolactinemia and tumor effects.

Patients with pituitary tumors who have signs and symptoms of Cushing's need formal assessment to rule out Cushing's. (Dr. Maria Fleseriu, Oregon Health and Science University)

A: An evaluation by a pituitary endocrinologist is necessary in cases of suboptimal response to dopamine agonists of tumors thought to secrete prolactin. There are several circumstances when surgery is considered, such as when there is resistance to medical treatment with dopamine agonists. The tumor appearance on the MRI and prolactin levels should be considered along with the clinical context. Other medications can interfere with the effect of dopamine agonists and should be carefully evaluated. Patients with hyperprolactinemia can experience weight gain, increased face and body hair, mood changes and abnormal bone mineral density, which are also manifestations of high cortisol. However, patients with prolactinomas do not usually have purple stretch marks, easy bruising, muscle weakness or significant changes in appearance. There are rare situations when a pituitary adenoma can secrete both prolactin and ACTH, or when 2 different pituitary adenomas are present in the same patient. Our group published an "intriguing case of a double pituitary adenoma" in the journal World Neurosurgery in 2019 (Gonzalez A et al) which gave us the opportunity to review the literature published on this topic. (Editor's Note: Check the Research Summaries section for a summary of this case) (Dr. Adriana Ioachimescu, Emory University Hospital)

Q: I had a surgery scheduled for July but the pandemic put that on pause. My doctor told me about some medications that are available to help control the cortisol until I feel safe going for surgery, but when I asked about them online it seemed like they are all poison. I've put off making a decision because these patients seem to know so much more than I do, and now I'm afraid to try ANY of these medicines. Is it ok for me to just "suffer in silence" until I'm ready to have surgery as long as I take the blood pressure and diabetes medicines?

A: Patients with Cushing's may benefit from taking medication to control excess cortisol, if surgery has to be delayed. Untreated, cortisol in excess can affect the body in different ways (for example, affect mood negatively, cause bone and muscle loss, increase the risk of infection, among others). So, if surgery has to be delayed, then medical treatment can be helpful as a temporary step. There are several different medications available, which differ with regards to their effectiveness and side effects. These medications can be helpful in improving symptoms and can be safe if properly monitored. A thorough discussion with an experienced endocrinologist is important in order to help you choose among medical treatment options and monitor medication effects. (Dr. Nicholas Tritos, Massachusetts General Hospital)

A: This is a challenging decision that entails balancing the specifics ofsurgery during Covid times and patient's clinical manifestations. Treatment is usually recommended for patients with unequivocally demonstrated and clinically significant Cushing's syndrome. Some complications sometimes come unexpectedly, such as infections, fractures or blood clots. There are several medications available for treatment of Cushing's syndrome which carry risks for adverse effects and medication interactions. An experienced endocrinologist could provide the patient with information to weight in the risks and benefits of the 3 approaches: 1) surgery, 2) medical treatment for cortisol excess and 3) medical treatment to control of comorbidities. (Dr. Adriana Ioachimescu, Emory University Hospital)

(Editor's Note: We have included an update on medical therapies available to Cushing's patients in this issue)

Q: Since the beginning of the pandemic I've told myself that if there was a vaccine clinical trial near me, I would enter it as fast as possible. Is there anything Cushing's related I should consider before entering a COVID vaccine trial? What about when there is an actual vaccine available?

A: When it comes to the COVID vaccination, theoretically it should not pose an extra risk to patients with Cushing syndrome as long this is an mRNA or non-active vaccine. With the caveat that we do not know what kind of immune reaction even someone in general population would mount, patients with untreated/uncontrolled Cushing syndrome (high cortisol levels) might have a lower antibody production in response to the vaccine. (Dr. Georgiana Dobri, Cornell)

A: When considering whether to join a vaccine study, it is important to read the consent form carefully to determine if you would be able to receive a non-investigational vaccine when it is available, since most of the studies will be running for 18 – 24 months. Some of the studies do not allow you to receive a vaccine, if one becomes available, until the study is done. If you participate, it is possible that you will receive an inactive injection (placebo) or that the vaccine itself will not be effective. If you want more information on the trials, you can go to the website https://ClinicalTrials.gov and enter "COVID vaccination" into the search engine, then go to the map and click on the country where you live. You will then be able to read about the study, what would allow you to be included (or not), the length of the study, etc. (Dr. Lynnette Nieman, NIH)

A: Patients in remission from Cushing's syndrome probably qualify for such trials, especially if they produce normal cortisol levels, i.e. they do not take glucocorticoids to treat adrenal insufficiency that can occur after surgery or radiation. At this time, we do not know much about the interplay between cortisol abnormalities and the immunity provided by an experimental vaccine for Covid 19 or its risks. (Dr. Adriana Ioachimescu, Emory University Hospital)

Prescription Assistance

There are many prescription drug cards that can be found by searching the internet. The CSRF does not endorse any specific card. One that has recently come to our attention is UNA Rx card which can be used nationwide. More information is available at http://www.unarxcard.com/index.php

Rx Hope is another program with discounted prescription pricing: https://www.rxhope.com/

PAN has programs for some of the medications specific to Cushing's including Korlym and Signifor: https://www.panfoundation.org/

NORD also provides help with medication costs as well as travel and other medical expenses: http://rarediseases.org/for-patients-and-families/help-access-medications/patient-assistance-programs/

Call: 1-800-999-6673 x 326
Email: Cushings@rarediseases.org

Cushing's and Blood Sugar- What's the Connection?

Mary Sikora-Peterson

I am writing this article from two perspectives- as a Diabetes Care and Education Specialist (CDCES) and as a person who has successfully recovered, hopefully forever, from Cushing's disease (pituitary surgery May 2018).

It has been estimated that about 70% of people with Cushing's have some type of impairment with blood sugar (glucose) according to Mattia Barbot et al. Some peo-ple will have mild elevations in blood glucose while others develop diabetes and require medications including insulin.

How and why does Cushing's increase blood glucose?

I will start with explaining the normal cortisol response to stress and subsequent effect on blood glucose in people without Cushing's:

1. A person is faced with a stressor, this could be an emotional situation or physi-cal issue such as an infection

2. ACTH (adrenalcorticotropic hormone) is released from the pituitary gland to stimulate the adrenal glands to make cortisol

3. Among other actions, cortisol will prepare the body for the fight-or-flight re-sponse by flooding it with glucose to supply immediate energy and decreasing insulin in an attempt to prevent glucose from being stored

4. The stressful situation is diminished

5. Cortisol levels return to normal

In the above process, glucose is increased only momentarily; therefore it usually does not lead to problems. However, with Cushing's there is always excess ACTH and cortisol floating around, so the negative effects on blood glucose and insulin are constant. This often leads to some type of abnormality in glucose metabolism such as glucose intolerance, prediabetes, or diabetes. If untreated, these conditions can lead to further complications.

Should every person with Cushing's be screened for glucose abnormalities?

According to the 2020 American Diabetes Association (ADA) Standards of Medi-cal Care, anyone over the age of 45, or who has a history gestational diabetes, or who is obese and has at least one of the following risk factors should be considered for diabetes/prediabetes testing:

- family history of diabetes
- history of polycystic ovarian syndrome (PCOS)
- lack of exercise
- high blood pressure
- high cholesterol
- heart disease
- certain races/ethnicities such as African Americans, Latinos, Native Ameri-cans, and Pacific Islanders

The guidelines also include "other conditions associated with insulin resistance" in this list. I would consider Cushing's to be such a condition although the ADA guidelines do not specifically state this disease.

Besides having any of the risk factors listed above, another reason to get screened is if you notice symptoms of diabetes/prediabetes which

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include increased hunger and thirst, excessive urination, and fatigue. However, note that most of these symp-toms can be common in Cushing's without regard to blood glucose levels.

In my case, I had only one risk factor but ended up getting fasting blood glucose and A1C tests done (A1C shows a 2-3 month blood glucose average). I was found to have prediabetes. I monitored my glucose at home and found my glucose to be totally normal during the day but then it often rose to high 200s at bedtime. Ac-cording to Mattia Barbot et al, this can be a typical pattern with Cushing's-related hyperglycemia (high blood glucose). These high bedtime readings may explain why I began to wake up four or five times a night to urinate copious amounts of clear urine despite purposely limiting fluids after 5pm. Based on my experience and the ADA guidelines, I recommend that all people diagnosed with Cushing's have some type of glucose testing performed, especially anyone with risk factors for diabetes/prediabetes.

Will blood glucose return to normal after treatment?

According to the CSRF website, Dr James Findling states, "Following recovery from Cushing's syndrome, diabetes is almost always easier to manage and may even completely resolve." In my case, my A1C went from 5.8 (prediabetes) with Cushing's to an A1C of 5.3 (normal) about six months after surgery. I was no longer having blood glucose readings in the high 200s at night, a decrease that oc-curred within 24 hours after surgery. Note that it can take some time to show an improvement in A1C due to this test being a three-month average. Also, it's possi-ble that a person with Cushing's can be diagnosed with diabetes/prediabetes un-re-lated to the Cushing's, so in that case the glucose issues would not resolve after treatment.

The good news is that blood sugar issues do often improve after Cushing's treat-ment. If you still have prediabetes or diabetes despite Cushing's treatment, be sure to work with your health care team which may include a physician, CDCES, dieti-tian, pharmacist, and exercise professional. They can provide support and educa-tion to assist you with developing a healthy lifestyle for blood sugar management.

Mary Sikora-Petersen is a CSRF member, Diabetes Care and Education Specialist, Registered Dietitian Nutritionist, and National Board Certified Health and Wellness Coach who helps patients manage chronic disease by adapting a healthy lifestyle.

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Mattia Barbot, Filippo Ceccato and Carla Scaroni: Diabetes Mellitus Secondary to Cushing's Disease. Frontiers in Endocrinology Jun 04 2018; 9:284

American Diabetes Association-Classification and diagnosis of diabetes: Standards of Medical Care in Diabetes 2020. Diabetes Care 2020;43(Suppl. 1):S14–S31

CSRF Website accessed 5/25/2020

Mary on her surgery day with active Cushing's.

Mary today, in remission

Research Summaries

Over the course of this year our Medical Advisory Board has shared many excellent articles of interest to Cushing's patients. For this preview issue we wanted to focus on a topic that our membership has repeatedly indicated as a high priority – knowing what to expect after surgery, especially regarding cognitive, neuropsychological, and emotional outcomes. In the full 2020 Year In Review issue coming next month we will cover a broader scope and include many of these manuscripts.

There have also been several articles and other resources related to Cushing's, adrenal insufficiency, and COVID which we have compiled over the year; you can find these resources by clicking the QR code or visiting https://csrf.net/news-events/covid-19-resources/.

In Spring 2020 a 136-question survey was designed by a Cushing's patient steering committee and completed by 178 members of CSRF. The survey was based on topics considered during planning of our biennial national patient meeting held in October 2019 and feedback from attendees at that conference. It is our intention to support current and future patients with this data, but also to give providers a deeper glimpse at the inner workings of what it is like for patients outside of the clinical setting. We believe that sincere dialogue with our care team, full disclosure, and all options on the table are imperative to successful treatment outcomes. As the data from our survey shows, we are nearly unanimous in wanting to know what to expect, in detail.

We are analyzing this data with assistance from Drs. Raj Mukherjee and Adam Khalafallah at Johns Hopkins University and will collaborate on an article to be released in early 2021 and shared far and wide while advocating for our community. In the meantime, if you would like to look at the full data set, scan the QR code or visit https://csrf.net/wp-content/uploads/2020/12/PDF-SURVEY-DATA-for-newsletter.pdf.

Neuropsychological and Emotional Functioning in Patients with Cushing's Syndrome

Sabrina Na, Mary A Fernandes, Adriana G Ioachimescu, Suzanne Penna. Behavioural Neurology.

2020, article id 4064370, https://doi.org/10.1155/2020/4064370

Changes in structure and function of the brain during Cushing's have been documented, and we patients know from personal experience the cognitive and emotional difficulties faced during active disease and post-op. Patients treated at Emory University Hospital in Atlanta, GA are referred for in-depth testing to the neuropsychology department, and doctors are now able to begin reporting data based on the collective results. This study compared 18 patients – 11 in active Cushing's and 7 in remission – on several points including attention, cognitive flexibility, and self-reported depression and anxiety. The goals of the study were to look at neuropsychological and emotional functioning with emphasis on attention and memory.

The results are complex and go into detail far beyond anything we could accurately summarize here, so if this is a topic of interest to you we enthusiastically suggest that you read the article in depth. Co-author Dr. Suzanne Penna gave a highly rated presentation on this topic at our patient conference in 2019; you can access that video and all other materials from that meeting at https://csrf.net/patientconference2019/.

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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!

Phoenix, AZ*
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Alberta, Canada
Alberta Pituitary Patient Society
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*support group

Lauren

Bethesda, Maryland

Until fourth grade, I had always been one of the tallest girls in my class. However, that year my parents noticed that my growth suddenly slowed. They immediately began to schedule appointments with various doctors to figure out the reason, all without success. The doctors all insisted that this was merely a phase and that I would continue to grow. Despite countless blood tests, they were unable to identify a reason for my lack of growth. After many more unsuccessful visits that took us all the way to New York, we reached a turning point when we were referred to the Children's Hospital of Philadelphia (CHOP). After a year of testing at CHOP for one unlikely disease after another, a pediatric endocrinologist finally checked my cortisol level, which no one had suggested before. That was it. My cortisol levels were very high, confirming her suspicion that I had Cushing's disease. Unlike the "typical" Cushing's patient, I had not experienced excessive weight gain, which is usually the classic indicator of Cushing's. My most noticeable symptoms were lack of growth and round cheeks, which is why it had been so difficult to diagnose.

However, our journey didn't end at CHOP. Next we were referred to the National Institutes of Health (NIH) to confirm the Cushing's diagnosis through more specialized testing. After the diagnosis was confirmed it took a few weeks of blood tests, X-rays, and MRIs to determine where in my body the tumor causing excess cortisol was located. The tumor turned out to be in my pituitary gland. It was clear that I would have to get transsphenoidal surgery (TSS) to remove this tumor, because leaving Cushing's untreated would not only inhibit my growth, it can also be fatal. This led us to our next step of figuring out which hospital and team would be the best to treat me. This was another long process and my family and I met with neurosurgeons in New York, in Bethesda, MD at NIH, and in Virginia. We decided that NIH was the best choice since they have a team of doctors that specialize in Cushing's, are leading researchers in the field, and are located within driving distance of us. From my first visit to NIH, I felt reassured by the skill and knowledge my doctors demonstrated and how they cared about their patients; I felt sure that I was in good hands. By this time, I was in seventh grade and we scheduled my surgery for that summer, before I entered eighth grade.

The day before my surgery, I was not allowed to eat or drink after midnight. When I arrived at the hospital the next day, the doctors drew seventeen vials of blood for various tests. I was very used to this from the past few years, but this was the first time that I felt queasy because so much was drawn. I still remember my last few seconds before being put under anesthesia, when I was talking to my anesthesiologist whom I remember as being very friendly and making me feel relaxed.

Post-surgery, I woke up in the ICU with a catheter, a plastic mask over my nose that blew out moist air and packing in my nose. My stuffy nose limited me to breathing through my mouth, and both were very swollen. That day as I took my first few steps after surgery, I was so weak that my vision went pitch black and I stumbled blindly when I stood up to get a drink of water. However, by the next day I was stable enough to be transferred to the pediatric day hospital. Two days after surgery, I was strong enough to be able to walk a bit by myself for the first time without getting dizzy, although I was required to use a wheelchair to get around. I took lots of naps throughout the day, and the nurses came to check my vitals and draw blood periodically. Some of my friends came to visit me and we explored the vast and amazing hospital. I was required to stay at NIH for ten days until I was stable enough to go home and to ensure that there had not been any complications from surgery.

While I had not been worried about the immediate risks of the surgery such as diabetes insipidus, it had been naïve of me to think that after surgery everything would be back to normal. Physically, the success of the surgery was clear. With a much lower cortisol level my cheeks became less puffy and round and I grew four inches taller that year. It wasn't until school started that I realized that despite this, I had a long way to go to recover. My cortisol level actually dropped to near zero and I had to take medication to bring it up to normal levels. I also had to take other hormone replacements such as to regulate my thyroid. I also needed to carry around a cortisol injection in case I experienced some type of trauma and had to wear a medical bracelet to identify my low cortisol levels. However, the cortisol replacement wasn't that effective and as a result, I experienced fatigue so extreme that I often physically couldn't keep my eyes open. This fatigue would come in waves during my classes throughout the day and I was constantly falling asleep in class. I tried different strategies such as getting up to get a drink of water but as soon as I sat back down I was just as tired. So, there wasn't much I could do to cope besides sleeping as much as possible, which meant sleeping in often and coming to school late, and often just falling asleep in class. Unsurprisingly, my fatigue took a severe toll on my grades and I went from a mostly A student to mostly Bs that year.

By the time I entered my freshman year of high school, I had mostly recovered although I was still often very tired and still didn't feel as if I was able to reach my potential academically. It wasn't until the end of the year that the doctors at NIH finally declared that my thyroid hormone and cortisol levels had returned to normal and that I was fully recovered. By sophomore year I felt as if I had regained the energy that I needed to accomplish what I was previous-

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ly capable of. My grades finally returned to normal and I was no longer falling asleep in class. Since my surgery, I have gone back to NIH a few times to participate in a study of post-surgery Cushing's patients, which will hopefully help future patients. I would like to continue to do more to help Cushing's patients and aid in medical research as well. Throughout this journey, I have been thankful to have the support of my family, friends, and of course the wonderful NIH team.

Recently, I was diagnosed with a recurrence of Cushing's and had a second TSS at NIH, under the care of the same team. They wasted no time between diagnosis and surgery; everything happened in the span of a few months. The surgery seems to have been successful so far, and I am so grateful for the support and expertise of the NIH team once again. None of us had thought that we would be in this position only a few years after my first surgery, but there is no one I trust more to help me through this disease.

Sidenote from Lauren's mom: I knew something was not right when Lauren first stopped growing. I was sure it wasn't "just a phase" she was going through; it was something more profound than being a "late bloomer" as we were told by many doctors. Despite being dismissed so many times, my gut feeling told me not to give up. For four years, not one doctor would take an overall look at Lauren's medical history and think about what the cause could really be. Refusing to take "no" for an answer, we kept taking Lauren to see different doctors and asking questions. Every time we met with a new doctor, we had to start over with bloodwork and repeat our story. It was emotionally and physically exhausting. It took us four years to meet someone at CHOP who finally thought of checking Lauren's cortisol level and that's how Lauren was diagnosed with Cushing's. We will never forget the kindness that was shown to us at NIH and the support we received from family and friends.

Looking back, I'm not sure if we could have done things differently. I only wish that doctors, especially pediatricians, would listen to parents and trust their instincts instead of waving them away so quickly. To parents whose kids are newly diagnosed with Cushing's, Lauren and I are happy to share our experience with you. Feel free to reach out!

Lauren and her Mom Li

(Editor's note: if you would like to send Lauren or Li a message, please e-mail it to leslie@csrf.net and we'll forward it on to them)

Bridget Houser

Chicago, IL

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My name is Bridget, and I'm a 31-year-old living in Chicago, IL. I was diagnosed with ectopic Cushing's in August 2019 and am now a little over one-year post-op. I had a partial lobectomy to remove a malignant Cushing's tumor on the lower left lobe of my lung. My ACTH and cortisol levels have remained low since surgery, meaning that the surgery was a success. I know that I'm one of the lucky ones - we found the tumor and had a successful surgery. Although everyone's story is a little different, I still find unwavering connections with every one that I read. I am thankful to be able to share mine with you now.

In 2016, I started experiencing daily headaches. I consulted with doctors, tried different diets, and even underwent LASIK surgery after convincing myself that my contacts were the cause. Knowing it was a common ailment, I wasn't concerned that an underlying health issue could be to blame.

The headaches continued, and then in early 2018, I started experiencing crippling anxiety and sought help from a psychiatrist. I was getting married later that year and my psychiatrist suggested that the underlying stress could have caused this "episode". While I didn't think I was harboring stressful feelings about my wedding, I accepted that it could be the cause and started taking anti-anxiety medication.

Shortly thereafter, I noticed I was gaining weight and my face became very round despite no change in my diet or exercise. I figured that it was an undesirable side effect of my anti-anxiety medication. Then, my hair started falling out. I went to my primary care doctor and started crying uncontrollably in her office as I explained what was going on. I told her that this is not what I'm supposed to look like. She told me that stress can have a big impact on the body, and that I should continue taking my anti-anxiety medication while searching for other ways to reduce my stress.

At this point, I blamed myself for what was happening. I thought that since I couldn't control my stress, I was ruining my life and now my physical appearance. I cried almost every day. I worked out twice as hard and

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ate half as much. My weight didn't budge. On top of weight gain, I was experiencing severe insomnia, night sweats, increased facial and arm hair, constipation, dizziness, acne (never had acne even as a teenager), and bruising.

A few weeks later, after worsening symptoms, I went back to my doctor convinced that I had thyroid issues. I had tests done that showed my thyroid was normal. My doctor referred me to an endocrinologist after I advocated for additional tests on my thyroid. Over the next few months, I saw two different endocrinologists who both confirmed my thyroid was normal and again spoke to me about stress. The second endocrinologist mentioned Cushing's, but because I didn't have some of the classic symptoms (purple stretch marks, hump, extreme weight gain), it was quickly ruled out. Regardless, I insisted on a cortisol test. She agreed to give me the test but said that she didn't think I had anything wrong with me.

Over the next month, I took three tests which all confirmed my cortisol was extremely high. My endocrinologist then diagnosed me with Cushing's. She said to me once again that I didn't look like the normal Cushing's patient. While I won't go into too much detail here, it is worth mentioning that getting all the tests, waiting for results, and communicating with the doctor were not fast or easy tasks.

I was referred to Dr. James Findling, a Cushing's specialist in Milwaukee. At my first appointment with him, he confirmed my Cushing's diagnosis and outlined next steps. My next step was to undergo the inferior petrosal sinus sampling (IPSS) procedure. The results showed that my tumor was not located in the pituitary gland; my tumor was ectopic, or located somewhere else in the body, which meant that I needed to undergo a series of scans to locate it.

A few days later, I had CT scans of my chest, abdomen and pelvis. The results showed no tumor. At this point, Dr. Findling explained that we would next try a dotatate PET scan of my chest, but that if we didn't see a tumor on this scan, I'd need to go on medicine to control my cortisol level and redo scans every six months until the tumor grew large enough for us to see it on a scan. At this point, I didn't think we'd find the tumor and I was preparing myself for the latter.

The following week, I had my dotatate PET scan, and this time, a tiny nodule on my left lung lit up on the scan. It was nothing short of a miracle in my mind. I had my surgery on October 30, 2019. The surgeon ended up removing the entire lower left lobe of my lung. On top of being a Cushing's tumor, the tumor was malignant and capable of spreading throughout my body. Though it was a slow-growing cancer, I am certainly happy that we caught it when we did.

Post-op, my ACTH/cortisol levels dropped dramatically, and they've remained low ever since. All the symptoms mentioned above have disappeared or reduced significantly. However, recovery has brought its own set of challenges.

The tricky part about recovery is that you start to look better but certainly don't feel better. Weaning off hydrocortisone leaves you tired and achy beyond belief. I've reached out to many other Cushing's patients in recovery which helps me feel that my struggles are a normal part of the process. I read in one patient's story how they compare their mornings to a feeling of being hit by one, two, or three trucks. While most mornings I do feel as though I've been hit by at least one truck, my spirits are much higher than when I had Cushing's because I know that I'm getting better.

I hope that my story can help someone else on their journey by providing hope, comfort, and/or education. Based on my experience, I have broken down my advice into the five bullet points below:

1) Advocate for yourself. Stress was an easy diagnosis, and had I not been more in tune with my body, I may have accepted that as the answer. It also helps to have others advocating for you. My husband was a huge help in calling doctors and making necessary appointments when I didn't have the energy to fight anymore.

2) Be nice to yourself! Looking back, I may have suffered less had I not blamed myself for what was going on in my body.

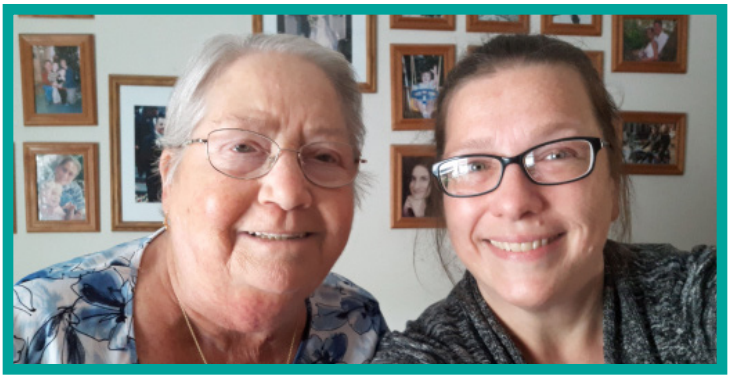
3) Get a support system and lean on them. For me this meant being vulnerable and admitting that I wasn't "okay" to my close friends and family. Having loved ones' support throughout this journey is critical.

4) Make sure you have the right medical team: get second opinions, meet with different doctors and pick your team wisely. A friendly conversation with reception and a quick call back from your doctor can mean the world when you're waiting on an important medical question or test result.

5) Give yourself time after surgery to return to normal. It is a long, tough recovery. Even more than a year post-op, I must be very selective as to how much energy I can exert in a day and devote lots of time to rest, relaxation, and sleep.

Good luck on your journey, I'm rooting for you and always remember, you are not alone!

Bridget with Cushing's



CSRF interviews one of its first members: Neddy Zaleski

Leslie Edwin

Neddy Zaleski joined CSRF in 1996 as one of the first official members when the organization was less than a year old. We conducted a mail outreach project earlier in 2020 to connect with patients who do not have e-mails listed in our database; when Neddy got her letter, she gave us a call.

I've always been curious about those early days of CSRF, from different viewpoints. Louise Pace, our Founder, has discussed the challenges and successes of getting it started, and Dr. James Findling shared in the last issue what it was like joining the Board many years ago. In the several hours that we ended up spending on the phone over two conversations, Neddy told me some of her story and memories she has of CSRF in the mid-90s. Over the years she has collected newsletters and correspondence into a file, so she pulled those out and described what she was looking at. Many times I thought to myself – I wish I could see these things! How can I get my hands on them?

Neddy and I discussed logistics, and one day in late May I snuck out of my house early in the morning to make the 3.5 hour drive to Charlotte, NC where she lives. We talked for over four hours. She entrusted me to become the new owner of her historical file. What follows is a short summary of her journey, with her approval, based on our conversations and the other details that were stashed away in storage with the newsletters.

Neddy Zaleski was born in 1943 and lived the majority of her life in New York. She was diagnosed with Cushing's Disease at age 53 and had two surgeries in September and October of 1996. Looking back, she's pretty certain that she suffered from high cortisol for at least a decade before getting an accurate diagnosis. Individual health problems would be addressed and treated individually; she spent years having countless doctor appointments across specialties and several surgeries. She suspects that, as a woman in her 40s and 50s, at least some of the delay was also due to gender bias in medicine.

In the beginning of her search for answers, Neddy says that doctors were obsessed with her weight. Most appointments seemed to end with the recommendation that she eat less, move more. She recalls that during that time, her kids would ask her why she kept going to the same doctors when they never seemed to help her get better. Her answer was a familiar one – "because they're doctors!"

Over the years she was tested and treated for numerous conditions – weight, blood pressure, vision disturbances, foot fractures – over and over, individual symptoms and conditions were treated without anyone seeing a bigger picture. One day Neddy fell asleep while she was driving. This scared her into another round of appointments trying to find out what was wrong, including a trip to the ophthalmologist to get her eyes checked. He found nothing wrong but recommended she get checked for diabetes….because of her weight. This time, though, the referral led her to the endocrinologist who finally made the correct diagnosis. After all those years, this specialist got it right after a simple office examination. "Don't worry, it's your adrenal glands, it will be like 1-2-3, you'll be a new woman in six months!" The actual source of her hypercortisolism took a little longer to figure out. After a week of in-patient testing, an MRI, and an inferior petrosal sinus sampling procedure (IPSS), doctors concluded that she actually had a pituitary tumor.

Neddy continued to work until her health deteriorated to the point where she could not do it anymore. She and her family had been planning a trip to Puerto Rico the summer she was diagnosed, so she delayed surgery to complete the travel. During this time she tried to read up on the condition, but the internet was so new that there were very few resources. The ones she found were confusing, and she reached a point where she just wanted it all over with. Continuing to gain weight, even though she now knew why, was also detrimental to her quality of life. She had virtually every symptom of Cushing's by that point. With so many significant problems, sometimes it just felt like it was all coming to an end.

Immediately after surgery, Neddy recalls doctors assuring her she would "feel better" without being specific about what that meant. There was no information about the long-term effects of hypercortisolism at the time. Neddy found CSRF right before her surgery and called Louise, who was still recovering from her own surgery at that point, for support and advice. She was added to the newsletter list and given a short spreadsheet of other patients who were open to receiving phone calls from new members. While Neddy found the community to be a godsend, she and the others still didn't have much to work with regarding what they could expect long-term from this disease they were battling. A realistic timeline for recovery was sorely needed. She agrees that many Cushing's patients suffer from depression that goes untreated after surgery – then AND now. Doctors and advocates are starting to understand and incorporate this now, but that doesn't do much for patients who had to struggle to recover with no research to browse, no pamphlets with 10 or 15 year data, nothing. This is the exact environment that led Louise to establish CSRF back in 1995 – patients and doctors need to understand what is happening, and what will continue to happen. Suffering in si-

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lence after dealing with the detriment of high cortisol for so long can put us in very dark places.

The year after her surgery, Neddy still did not feel "back together". Her first grandson was born that year, and as much of a joy that he was, it was overwhelming. After spending "new mom" time with her daughter, she went to visit her brother in Florida for a few weeks. She just needed a change of scenery, some peace. Her adult children had made some efforts to understand what she was going through after she got her diagnosis, but as there was very little information available for patients, there were even less resources for family members and caregivers. Neddy had had one back surgery before her diagnosis, and in the five years after surgery she had four more. Even when she finally lost the weight that had been packing on over the years, she didn't feel great. I asked her, if before Cushing's you were "at 100%", where would you say you were afterwards? She was unable to answer the question because she had too many ongoing problems for so long.

Now, almost a quarter of a century out, I wondered if Neddy had concluded anything from her experience. She said she has learned how to speak up and say how she feels rather than editing or excluding the truth for fear of negative reaction. She's more careful to protect herself from being hurt. Volunteering was one of her best coping mechanisms. She also found peace and comfort in hopeful songs and poetry, and had a couple of poems she wrote about her experience with Cushing's published on poetry.com in 2000, including this one:

A Second Chance

By Neddy Zaleski

Feeling sad, feeling blue

O, you know what to do

Take it one day at a time.

And you'll get thru

This most horrible nightmare

That you're so scared

To go thru

Think of life, think of fun, smile

You're number one

Fear, fear, go away

I need to be released from you

Let me go, let me go

Let me have, the peace

I should know.

These past few years Neddy has mostly felt "ready to move on" from her Cushing's experience. She's brought the last several issues of the newsletter to her local endocrinologist because she's no longer in an active state of searching for answers. She has ongoing health issues but does not attribute them to Cushing's. She lives in a quiet community outside of Charlotte, NC with a feisty little tuxedo cat named Junior. She feels that her experience with Cushing's has made her more empathic and understanding, even with people who don't have Cushing's. I asked her for advice she would give to patients these days. She says: "It's going to be a little bit of a haul, but don't hold back on what you're going to go through. It's going to take some time. Continue seeing your doctor and go for some counseling. It will help you through the rough times that you are going to go through. There will be good times. There will be rough, dark days. But it all passes in time. You have to be patient. It's so hard in the moment, but it's so important."

Thank you so much for spending time with me, Neddy, and sharing your CSRF archive!

Before Cushing's

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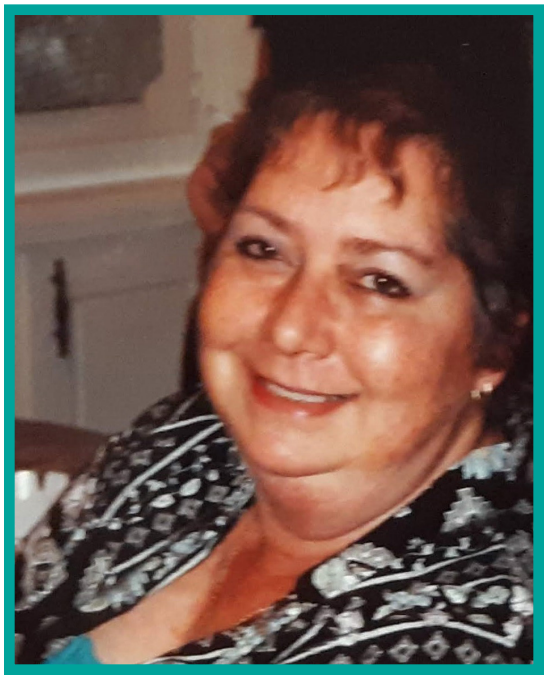

During Cushing's

In remission

We need your patient and recovery stories!

If you are interested in having your story in the CSRF newsletter, please email it to cushinfo@csrf.net or use Share Your Story under the Quick Links on our homepage.

The CSRF Medical Advisory Board

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