Cushing's Support & Research Foundation
Fall 2018

cushing's newsletter

SHARE • AID • CARE

Inside this issue

Discovering Your Voice: Advocacy After Cushing's

Marie Conley and Amy Dahm

The Merriam-Webster dictionary has a three-pronged definition for the word advocate: one who pleads the cause of another; one who defends or maintains a cause; and one who supports or promotes the interests of a cause or group. From that definition alone, you can probably think of many things for which you are an advocate in your own life. We are moved by our experiences and those of others we care about, so it's inevitable that the Cushing's journey leads to advocacy for some of us.

The following firsthand accounts come from Marie Conley and Amy Dahm, two women who have experienced Cushing's, Adrenal Insufficiency (AI), and many other cortisol-related complications in their lives. They have both used their existing skills, interests, and resources to effectively advocate for our community. By sharing their stories, we hope to encourage you to know that you are capable of advocacy using abilities and interests that you already possess.

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NEWS AND UPDATES

CSRF Newsletter Design: Heather Shaw
www.heathershawdesign.com

AFFILIATIONS
American Diabetes Association (ADA)
The Endocrine Society
European Society of Endocrinology
EURODIS (Rare Diseases Europe)
Global Genes
National Organization of Rare Disorders (NORD)
The Pituitary Society
World Association of Pituitary Organizations (WAPO)

FOLLOW THE CSRF ON TWITTER!
We will be tweeting whenever new content is added to our website or there is breaking news. To follow us, sign up at:

https://twitter.com/CSRFnet

Membership Update

As of July 1, 2018, all memberships to CSRF are now free. We are in the process of updating our system and signup avenues to reflect this change, and everyone currently in our database is converted to this new status. In early 2019 we will roll out a more specific definition of membership and its benefits. In the meantime, we thank you for supporting our efforts!

One big difference that will come with this update is the format in which you receive the newsletter. In an effort to control expenses and encourage consideration of financially supporting our mission, we will make the following changes beginning with the Winter/Spring 2019 issue:

- Members who have made any donation since July 1, 2018 will receive the three 2019 issues of the newsletter in print or immediate digital delivery, as desired. If digital delivery is not specifically requested, this will automatically default to print.
- Members who have not made a financial contribution since July 1, 2018 will receive the newsletter in digital format via e-mail approximately one month after each print issue is delivered.
- A donation in any amount at any time will trigger a print (or immediate digital) subscription for the following three issues. We believe in the concept of "small and many make much"; there is no such thing as an insignificant donation! $1.00 allows us to send two pieces of mail. $5.00 is the cost to create one newsletter that will end up in the hands of a newly diagnosed patient via their doctor's office (we distribute multiple copies to dozens of high-volume centers). $15.00 covers a mailing to an endocrinologist with two most recent issues of the newsletter and other educational materials with an invitation letter to contact us for more information and a source for patient peer support. $25.00 covers the actual cost to produce and mail three newsletters per year. We ask that you consider a donation in whatever amount is best for you, because we need your support to expand our outreach programs and efforts to educate and support the professionals who are seeing members of our community at all stages of their journeys.

THANK YOU FOR BEING A MEMBER OF CSRF!

SAVE THE DATE

Update on the Treatment of Pituitary Diseases: Emerging Therapies

Memorial Sloan Kettering Hospital, New York, NY
April 12, 2019

Marie

I wonder if people like Theodore Roosevelt, Maya Angelou, and E.E. Cummings ever thought that their words would have such an impact on a person that they would redirect their life efforts to help a community in need of advocate voices.

I was diagnosed in 2012 with Cushing's Disease after years of tests, specialists, diets, frustrations, and no resolution as to what was happening to my body and my mind. While I believe I am a "glass half full" kind of person, I found myself wanting to not only knock the glass over but crush it in a million pieces! Theodore Roosevelt's words from *The Man in the Arena* helped me get through these tough times. To paraphrase, when you believe in a worthy cause, put yourself out there and try to do something about it. I also made a deal with God: "You get me through this and I will take my tenacity and all of the professional skills I have and do something to help others like me." That is what I have done.

There are many things Cushing's patients can commiserate about, but two things affected me the most: the lack of information available for my husband, parents, family and friends, and the fact that when I was ready to talk, it was hard to find anyone near me that was like me. I was also disturbed to become aware of how little the medical community knew about our disease. I wanted to help change that.

In 2014, I created The Conley Cushing's Disease Fund (a project of The Foundation for Enhancing Communities, fiscal sponsor). The funds raised are used to create awareness and advocacy for patients and their loved ones who are suffering from this disease, as well as to support institutions and organizations focused on research and treatment surrounding Cushing's.

With the encouragement of my doctor and parents, I then self-published emails I wrote to family and friends in a book called *A Cushing's Collection.* It begins three weeks before my diagnosis and runs through a difficult and complex journey like so many others experience: a failed brain surgery, removal of my adrenal glands, removal of the lower right lobe of my lung, and trips upon trips to the ER. It also deals with the reality of telling our five-year-old son that "Mommy has a boo-boo in her head and the doctors will help me feel better." It shares the realization that I needed to learn that I am not who I was, and I needed to learn a "new normal." It describes my envy and frustration that dogs and horses get more 'publicity' about this disease than humans. Please note, I am the furthest thing from a writer and have no experience at all in this world, but I researched and called around and was able to turn this into reality. I am honored when I hear from people who have read it. I'm humbled when family members share that they have a glimpse into the world that their son/daughter/wife/husband/niece is going through. All net proceeds from the sale of my book go directly back to the Fund.

14 Cushing's patients were deemed "Superheroes" at the 4th annual Kickin' Cushing's to the Curb – Superhero Style reception in Hershey, Pennsylvania on November 17, 2017

When I was finally ready, I wanted to meet others like me. With the help of CSRF, word of mouth, and local hospitals, we now have an amazing group of patients within our support group. Our group is informal and meets about four times a year but communicates with one another often. We meet outside of Philadelphia but have patients participating from the four surrounding states.

In November 2014, I planned and executed the Fund's first annual fundraising and awareness reception in Hershey, Pennsylvania. Cushing's patients and their families are the special guests, and the festivities and celebrations revolve around them. We also have a patient and family breakfast the following morning. I used past relationships to leverage support and awareness in any way possible. I wasn't sure what would happen that first year, but I knew that any money I raised was more than I had the day before to support the mission of the Fund. I cashed in every professional and personal chip I had to make the event a success. I would be the first to say that coordinating a large fundraising party is not the easiest tactic one should use to help raise funds, but I was a professional event planner and fundraiser, so this was a natural fit for me. The dollars raised at the event not only support the patients and families, but also help increase awareness for medical professionals for early diagnosis through lunch and learns with medical students, CME classes for medical staff, and grand round presentations.

I have taken all the professional skills that I have acquired in the past 20 years, my tenacity, a great contact database, and a lot of luck (and hydrocortisone) and have been blessed with the ability to do this. I know I am unique. I know I am very lucky because I work from home. I know I am fortunate to have extremely supportive parents who help me stuff envelopes and drive with me to places. These attributes have allowed me to help in this way. Given my health, I have learned the hard way how to manage my time between my family, our home, my

continued

job, and my advocacy. I have pushed it and ended up on the couch (or in the ER) when I didn't manage my energy output. There are days that I just can't get the job done and need to wait for tomorrow! There are days I can't get out of bed. I just try my best and I hope that my efforts in some small way help some patient or some undiagnosed person not have to go through what I have gone through, or some family member to have a better understanding of what their loved one is going through. I hope that through awareness, a medical professional will take another moment, recall what they heard in "that Cushing's class," and re-evaluate the patient in front of them.

I don't want to break the glass of water anymore, and I refuse to see it as half empty. I do accept that on some days the glass of water is murky and unappealing, but it's never empty. This disease has won a few small battles over the years, but it won't win the war!

I recognize I am in a unique position to do what I do, but when it comes to advocacy there is nothing too small. If I can help you assess how to leverage your strengths so that you can do something, please contact me at marie@kickcushings.com. Like John F. Kennedy said, "One person can make a difference, and everyone should try."

Editor's Note: *Marie has been working with the National Organization for Rare Disorders (NORD) to coordinate the Pennsylvania Rare Disease Press Conference in Harrisburg, PA for the past three years. She also helped create and was then appointed by the Governor to serve on the PA Rare Disease Advisory Council. You can find out more about Marie, the Fund, her book, and events at kickcushings.com.*

A Cushing's Collection: A Humorous Journey Surviving Cushing's Disease, Diabetes Insipidus, and a Bilateral Adrenalectomy, *referenced in this article, was self-published by Marie. Over the years we've met several patients who have been so deeply affected that they similarly self-published records of their Cushing's experiences. If you have ever wanted to write something, there are many free self-publishing resources online as well as publishing companies that offer tools to make your work more polished and professional.*

Amy

If someone had told me after my surgery in 2014 that I would appear on CBS radio with a celebrity fitness trainer, be filmed for a documentary about bias and women's health, lobby Capitol Hill to increase funding for the National Institutes of Health (NIH), help develop an Adrenal Insufficiency (AI) protocol for service dogs, or do a podcast on "my Cushing's journey" – I would have laughed. At the time I couldn't even put my pants on or open a pickle jar.

My journey into advocacy has been fairly organic and full of unexpected friendships, turns, and experiences. What has been driving it throughout is a desire to learn as much as I can about Cushing's, a commitment to secure the best possible care for our community, and a desire to "show up" and be a face and voice for our concerns. In many ways, it's also been a subconscious exercise for validation and to try to find meaning in an isolating, physically grueling, demeaning, and painful experience. If there is anything I can do to minimize others' suffering…I want to do it.

BECOMING A PATIENT

When I went to NIH for my testing, treatment, and surgery, I was cast adrift into a completely unfamiliar environment full of terms I did not understand, beeping machines, and invasive tests. I felt helpless. But it was such a relief when I met other people like me and doctors who had seen and treated other people like me. When I asked about patient support groups, one of the nurses mentioned that there was an organization that published newsletters and one of the "alumni" patients suggested I check out CSRF.

After I came home, I quickly realized that I had to learn as much as possible about how to manage my illness – my life literally depended on it. It was going to be a month before my regular endocrinologist could see me and I was in the throes of withdrawal with skull-splitting headaches; I was having difficulty distinguishing low cortisol (hellish) vs. adrenal crisis (life threatening). Cushing's, like any rare illness, demands that the patient educate herself and steer her own ship. I would not be able to rely solely on my doctors; I had to rely on what my own body was telling me. I had no tools to measure my variable cortisol levels except my own body's symptomology – and high cortisol and low cortisol often had similar symptoms. My Cushing's "fairy godmother" Tasia sent over an AI patient guide and told me to check out some of the online patient groups, or boards. I signed up for the ones that had the most people and started to realize that they each had their own personality and purveyed different information. The press officer in me signed up for all of them because I wanted the most balanced information landscape possible. I wanted to help answer other people's questions, but realized that until I became super-educated about the illness – I would not be able to be an effective member of the on-line community.

ADVOCATING WITHIN THE CUSHING'S COMMUNITY

Through one of the CSRF newsletters I learned about the CSRF National Patient Education Day in Atlanta, Georgia. I could not believe my luck! Less than a month after my surgery there was going to be a national conference focused on all things Cushing's and full of Cushing's patients. I really wanted to go, but was afraid to travel so soon after surgery. When I discussed it with my boyfriend, he volunteered to go with me.

The CSRF Conference was a revelation! Some of the medical field's brightest minds were presenting, and I got to speak with so many other Cushing's patients that were in various stages of recovery. For the first time I saw there was a light at the end of the tunnel; it gave me hope. I met a mother-daughter pair of Cushing's patients, and truly saw there is life after Cushing's and what that looked like. I was shocked and horrified, though, when one woman told me although it was tough, she had worked throughout and had not taken any time off of work. I was flabbergasted – she had worked through BRAIN SURGERY?! And then someone told me that many doctors do not consider pituitary surgery like actual brain surgery. I was like, "How is this even possible?" I also noticed that although all of the male patients had partners in attendance with them… only two female patients (out of an entire roomful of people) did. This underscored the need for more support for patients.

ADVOCATING WITH FAMILY AND FRIENDS

One of the hardest aspects of Cushing's is learning how to advocate within your own community amongst family, colleagues, and friends. This is difficult because they have no frame of reference, have never heard of the disease, and there is a large social bias against middle-aged female patients and diseases that make them fat, ugly, and emotionally unstable. Although my doctors warned me about the psychological symptoms, my friends and family were not prepared for the psychological, physical, and personality changes that Cushing's rendered (and quite frankly, neither was I). Even my newly curly hair (much less all of the other stuff) threw my Mom and sisters for a loop.

At work, I had to weigh how much to tell people with the stone cold reality that I would be gone for two months – and possibly more. My team was going to have to cover my work or bring in someone to cover it for me. No one had heard of Cushing's; they literally had no frame of reference. At that point, I was still trying to manage my "corridor reputation" and was leery of informing people that I would have cognitive deficits because of the adrenal insufficiency. Plus there was the whole issue of informing people how to administer an emergency shot in case I went into adrenal crisis. It was an exercise of balancing privacy and discretion with my new medically fragile reality. Plus I was worried that any information could be exploited and used against me, and any requests for accommodation would be viewed as weakness.

NORD RARE DISEASE SUMMIT

The NORD Rare Disease Summit was my first glimpse of what is possible with rare disease advocacy and how it felt to be part of the rare disease community. Since I lived in DC, I signed up as an individual patient and met up with Leslie Edwin as a representative of CSRF. NORD gave me a scholarship that covered the cost of my registration fee. I met other AI disease advocates and observed the importance of showing up, speaking up, and being politically organized; diseases even rarer than Cushing's were receiving more funding, resources, and advances, in my opinion because they were politically astute. At the resource fair, I marveled at the different types of resources available, including the NIH Rare Disease Hotline and free patient transportation. We could book one-on-one meetings with pharma companies and attend sessions that taught us the latest medical trends, breakthroughs, and how to interact with the FDA. One of my business school colleagues was a panelist, and seeing him made me think, "I can do this."

CSRF DC PATIENT SUPPORT GROUP

As I was starting to recover, two long-term members of the CSRF, Stacy and Renee, began a DC/ MD/ VA Cushing's patient support group. Our first meeting was at a local Starbucks and it was such a relief to meet other Cushies in the flesh to talk about our illnesses, our stories, approaches, and treatments. Over time, one of our local Cushies, Georgina, offered to host the meetings in her home. These gatherings enabled us to compare notes and mentor new patients and each other.

JOHNS HOPKINS PITUITARY DAY

Several of the patients in my support group told me about Hopkins Pituitary Day and it piqued my curiosity. I felt uneasy because 1) I am an adrenal patient and 2) I'm not a Hopkins patient. I called them up and they graciously agreed to let me attend the conference. It was cool meeting patients from all over the mid-Atlantic region, and I watched in awe as Mike Scalise, an Acromegaly patient, got up and read from his book, *The Big Catastrophe.* He articulated so many experiences that resonated with me (like going into adrenal crisis during an important family occasion). The first half of the conference included presentations from world-class endocrinologists, pituitary experts and patients. The second half was a chance to sit down at different tables and ask questions of these experts in a relaxed setting. Later, when Mike came through DC on his book tour, I organized a Cushing's patient dinner with him.

MAKING SAM INTO AN AI SERVICE DOG

After my dog, Sam, naturally alerted on me one night, I researched local trainers in the area and he and I went and trained with a renowned diabetic alert dog trainer. The trainer and I had a "Eureka!" moment where we worked out that each dog would have to be trained to the owner – and could not be universally trained – unlike diabetic alert dogs, because it seemed each AI patient has a different "cliff."

At the CSRF 2017 National Patient Education Day, I held a side session where I presented about service dogs in general and my experiences with Sam in particular. Over time, as we became more attuned to each other, I would bring Sam with me to the Visitor's Center of the National Capitol for Rare Disease Week, panels, discussions, movies, and lobbying on Capitol Hill. He helped to make Cushing's and AI, an invisible disability, more visible.

NIH RARE DISEASE DAY

While coming back for checkups at NIH I noticed information about the NIH Rare Disease Day at the end of Rare Disease Week in February. There was a full day of presentations about the newest technol-

continued

ogies, like CRISPR, as well as patient panels, best practices, and a "disease fair" of information and resources. While touring the disease fair I met the leader of the rare tumor clinic in person.

LOBBYING AND RARE DISEASE WEEK

Shortly after I started training him, Sam and I attended a session in the Visitors' Center of the Capitol to kick off Rare Disease Week, as I assumed that others would have their service dogs with them as well. After everyone clapped during one of the presentations, Sam started barking in unison. I learned that there is a whole group of Congressional representatives dedicated to rare diseases, the Rare Disease Caucus. One of the members of the Congressional Rare Disease Caucus got up and addressed his audience, "I am proud to be here to represent my constituents, both human and canine…" while Sam beamed and the audience laughed. At the event we heard about a chance to go and lobby our Congressman. I really wanted to go… but it was necessary to register in advance.

The next year I kept my eyes open for information about the lobbying event and registered for all Rare Disease Week activities. There was a full roster of events, including a film screening, art show, information sessions, a lobbying training workshop, and the actual lobbying day itself. It was all free. Sam and I enjoyed the pre-screening happy hour and connecting with other rare disease advocates.

In the lobbying workshop, we took a class that taught us how to present our "elevator speech" and then in the afternoon met with our state delegations. As a DC resident, the organizers assigned me to the VA delegation, which was huge at 30 members. The group chose Sam and me to be one of four speakers to the offices of VA Senators Tim Kaine and Mark Warner, and we were each given a schedule. Each speaker had about 3-4 minutes to tell their stories and in my case, appeal for additional funding for the National Institutes of Health, where I had been a patient for years.

The day of the lobbying we met up in the Rotunda beforehand and took photos before heading to the Senator's office. One of the most seasoned rare disease advocates introduced us, and the Senator's staff welcomed us. The first speaker was a man and father of four who had lost all four of his children to lymphedema. I spoke about NIH funding, and another woman discussed her husband's fight and decline, and how it had impacted their family.

One of the other members of the delegation was a rare disease advocate who had a film crew following her. One of the crew members stopped to say hi to Sam, and I found out they were filming the documentary "Miss Diagnosed" – a documentary about bias against women in medicine. They interviewed me on the spot and I shared with them how difficult it was for Cushing's patients, who are primarily female middle-aged women, to get diagnosed, in part because of bias. After the lobbying I had lunch with my friend Alison, a fellow Cushie from Boston. We met a glamorous Maryland beauty queen, who also happened to have AI and is a huge advocate within the community. A woman named Diane Silverman and I also hit it off – she was a Development Consultant for the newly-merged PheoPara Alliance and we vowed to keep in touch.

CBS RADIO SHOW

In Fall of 2017 Shianne Lombard-Treman reached out to me and asked if I would be interested in going with her on the radio to promote Cushing's awareness and her new book about Cushing's. I said, "Sure, I'd be happy to!" We drafted potential questions and answers for the interview and had a pre-interview call with Baltimore radio personality Gina Crash. The next morning at the studio we discovered that all three of us were Sicilian. Shianne's husband, Tom, stopped in, and we had a blast – the interview felt like three girlfriends chatting and flew by.

I was devastated several months later when Shianne committed suicide as a complication of Cushing's and Bipolar Disorder. She looked so good on the outside that it was difficult to gauge what a difficult time she was having.

THE EMPOWERED PATIENT PODCAST

In Spring of 2018 while meeting up with one of my business school classmates and his family, I confided that I had been a Cushing's patient. He himself had also been diagnosed with a chronic illness, and demonstrated kindness and empathy when I told him. He encouraged me to do a segment of the "Empowered Patient" podcast (empoweredpatientradio.com), and introduced me to the producer. The producer and I hit it off. We did the interview over the phone, and she asked me a series of thoughtful questions that highlighted the challenges of being a rare disease patient.

PHEOPARA ALLIANCE GALA

In Summer of 2018, my friend Diane reached out and invited me (and Sam!) to the PheoPara Alliance Gala. It was inspiring to see and experience such a wonderful event. The fundraiser had a cocktail hour, dinner, and then post-dinner auction at a nearby hotel, and I learned that the entire organization was funded by a private family with no ties to the illness – the family saw an opportunity to make an impact in the rare disease space and took it.

HOW YOU CAN GET INVOLVED

There are so many ways to get involved: going to conferences, lobbying your state senators, serving on patient boards. Basically, I just kept saying "yes" even if I had never done it or wasn't sure what to do. If any of these sound appealing, please let me know and I am happy to send you in the right direction.

My goal is to have a whole phalanx of Cushing's warriors at the next Rare Disease Week, lobbying on Capitol Hill, or at the next rare disease conference. I want media blanketed with stories about Cushing's survivors, patients being asked to present our stories at medical conferences, and patients to serve as patient liaisons with the FDA. Part of this entails becoming more involved with the rare disease community as a whole.

Some potential next steps I see for our community are:

- Creating a Cushing's registry for research purposes
- Becoming involved with the FDA Patient Process
- Creating a patient-centered Cushing's/AI patient "workbook"—this is Shianne's idea
- Creating a diagnosis and rehabilitation center for Cushies

Please feel free to reach out to me at a_dahm@yahoo.com or 202-550-5088 if you have questions or ideas to discuss.

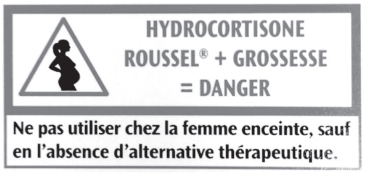
News from France:

NEW HYDROCORTISONE LABELING GETS QUICK RESPONSE FROM FRENCH SOCIETY OF ENDOCRINOLOGY

The French Society of Endocrinology (SFE) has put out an alert about a warning printed on packaging for hydrocortisone in France. It features an image of a pregnant woman inside of a red warning triangle and states that "hydrocortisone plus pregnancy equals danger." The label further states that hydrocortisone should not be used in pregnant women except in the absence of therapeutic alternatives.

The SFE has joined with another group to ask the French National Agency for Medicines and Health Products Safety (ANSM) to remove or change this potentially confusing label because hydrocortisone use should never be stopped in a patient with adrenal insufficiency (AI), even a pregnant one, unless there is a verifiably acceptable alternative treatment.

Most patients with AI quickly learn to be their own advocate and hopefully know that their vital need of replacement cortisol transcends all concerns about its potentially detrimental effects in other conditions. In the case of this particular issue though, an OB/GYN who is not familiar with AI but is familiar with the damaging effects of hydrocortisone and other steroids on the development of a fetus might ask if this medicine can be discontinued. We know the damage that can be done through miscommunication or not speaking up in a doctor's office. Hopefully this action by the SFE will create an opportunity to increase awareness.



HYDROCORTISONE ROUSSEL® + GROSSESSE = DANGER

Ne pas utiliser chez la femme enceinte, sauf en l'absence d'alternative thérapeutique.

OBSERVATIONAL STUDY LOOKS AT PATIENT AND PARTNER PERCEPTION AFTER REMISSION FROM CUSHING'S

The CSRF is a member of the World Alliance of Pituitary Organizations (WAPO), and they put out a quarterly newsletter called The Global Pituitary Voice in which member organizations are encouraged to share updates or other information about the work they are doing and change they are seeing in their countries. In the September 2018 issue, the Association Surrénales ("Adrenal Association") wrote about participating in an observational study that was looking at the way a patient sees themself compared to how their partner or close friend sees them. This observational study uses a series of seven types of questionnaires to get input from the patient. The patient's loved one is then asked to consider themself as the patient and answer just the first three questionnaires:

- Quality of life
- Depression
- Hospital anxiety and depression
- Management of the disease
- Self-esteem
- Body size and perception related to the changes it has gone through
- Coping abilities

Dr. Frederic Castinetti at the Assistance Publique Des Hopitaux de Marseille, France was the contact on this study. He reports that they completed registration of 40 patients ahead of the published estimated schedule, and they will give us a report of the results when they are available in several months. You can read all the details about this study on clinicaltrials.gov; search for study NCT03607474.

Need to talk?

Turn to page 23 for CSRF local support groups and contacts.

Your Unsolicited Ticket to the Chronic Illness Roller Coaster

Leslie Edwin and Dr. Ann Steiner

THE EXPERIENCE OF CHRONIC ILLNESS

If you have ever felt like no one in your life can truly comprehend what it's like to survive through the experience of Cushing's, maybe it can be a small bit of comfort that virtually 100% of patients report some level of misunderstanding, ignorance, and even intolerance from friends, family, and co-workers. Sometimes there are one or two curious people in your circle who take the time to research the disease, but for the most part it seems like the enormity of what's happening inside us is lost on most audiences. Conversely, our loved ones' protective intentions can also lead to suffocating and coddling behavior "for our safety."

For many of us, managing how a chronic illness fits into our lives becomes a piece of the puzzle to juggle after treatment. Living with an invisible illness is frustrating and isolating, but in some cases it can lead to depression, significantly reduced quality of life, and other situations where patients might need to be their own advocate – again! – to make sure their mental health is prioritized.

Dr. JoAnn LeMaistre is a psychotherapist and speaker who learned she had Multiple Sclerosis at a pivotal point in her life – she had just had a baby and gotten her PhD in clinical psychology. She wrote a book called *After the Diagnosis: From Crisis to Personal Renewal for Patients with Chronic Illness.* This amazing quote comes from her book:

> *"Central to wellness is the concept of adaptation – the flexible, creative use of resources to maximize your choices and experiences of mastery. This is the key to creating and sustaining a sense of inner tranquility in the face of difficult realities. There is no need to deny grim facts of existence or to pretend to others that all is well when inside there is little except torment. To be psychologically well while physically sick involves the belief that your personal worth transcends physical limitations; you need positive self-esteem for true adaptation. This belief in your self-worth rarely emerges until what you have lost and grieved for stands second in importance to precious moments of inner peace and joy."*

In *After the Diagnosis,* Dr. LeMaistre summarizes six stages of normal emotional reactions when a chronic illness like Cushing's becomes a part of your life. They can come in any order, they often repeat, and not everyone goes through each one. Family support and the patient's mental state, flexibility, personality, stress tolerance, and other characteristics play roles in how each stage is experienced.

- CRISIS – The patient is seriously ill, scared, and consumed with the emergency of the illness. Those around the patient usually have no problem understanding what is happening because it is the focus of everyone's attention. Survival is the #1 goal and most things are muted in favor of hyperfocus on the patient. No one knows what's going to happen.
- ISOLATION – The illness has settled in and the initial crisis has probably calmed down a bit. Everyone's starting to comprehend that this is going to be around for a long time. The patient is frequently depressed and anxious about their new dark passenger. Family and friends are also exhausted at this point.
- ANGER – The most dangerous stage has the patient usually blaming themselves for the illness that is disrupting everyone's lives. The worst possible outcome of this stage is suicide. The patient sees themself, not the illness, as the cause of the problems. There is heavy strain on the family.
- RECONSTRUCTION – The patient is better or is successfully using adaptive skills. Time is no longer frozen and everyone can look to the future with the "new normal". The most important element of life to be reconstructed is our emotional state.
- INTERMITTENT DEPRESSION – Dr. LeMaistre describes the "phantom psyche" that shows up and causes you to think if only you didn't have this disease, you could be doing things as you did before. It presents unrealistic expectations. Outwardly, what to us feels like introspection is frequently misread as self-pity. Anniversaries trigger memories and sadness.
- RENEWAL – No longer focused solely on adjusting and adapting, this is an opportunity to look at what we CAN do, and start doing it.

Alpine Guild, publisher of Dr. LeMaistre's book, offers an extended excerpt on their website from *After the Diagnosis* that goes into much more detail than this. We highly recommend you read it to get the full impact of her wisdom on this subject. Find it at **alpineguild.com/COPING WITH CHRONIC ILLNESS.html** (must capitalize the second half of the web address, and the spaces between the words are intentional and are not dashes or underscores).

COPING WITH A CHRONIC ILLNESS

Dr. Ann Steiner, psychotherapist, is another expert on this topic. She presented at a Cushing's Awareness Patient Day several years ago and shared resources about depression and coping. Dr. Steiner thinks it's important to consider the family messages we got when we were

PAIN/ENERGY PRICE INDEX

DESIRED ACTIVITIES	EMOTIONAL BENEFITS	PHYSICAL COSTS	COST/WORTH THE PRICE?
Gardening	Pleasurable outdoor activity. Feels like a contribution to family. Sense of competence and independence.	1 day of modified bed rest to recuperate plus no driving, typing, and cooking for 2 days.	Moderate/Worth the price once a month.
Sewing	Pleasurable activity. Feels like a contribution to self and family. Outlet for creativity. Sense of competence and independence.	2 days complete hand rest, or 1 day hand rest if sew only 10 min. every half-hour.	Moderate/Worth the price twice a month. May require giving up activities with equal physical demands.
Vacuuming	Necessary for clean, healthy environment. Exercise. Feels like a contribution. Sense of independence.	3 days of pain and restricted mobility if more than 5 min. at a time.	Moderate/Not worth the cost. Decide to have children vacuum in exchange for help with their homework.
Dancing	Joyful activity, socially rewarding. Exercise.	5 days of pain and increased symptoms or joint damage.	Severe/Occasionally worth the cost of pain since this level of enjoyment is rare.
Yard Work	Pleasurable activity. Exercise. Contribution to family. Sense of competence.	3 days of pain, restricted activity, increased sleep disruption, unless done no more than 10 minutes at a time with frequent rests.	Severe/Worth the cost.
Washing dishes	Necessary chore. Feels like a contribution.	Several hours increased stiffness pain and swelling of hands.	Moderate/Worth the cost when no one else can do it.

Copied with permission from the author, Ann Steiner PhD

growing up that shaped the way we conduct ourselves as adults. Are we conditioned not to ask for help even when we need it, for fear of imposing or being ridiculed? Was complaining met with help and comfort, or ignored? What subtle signs did we receive about being a burden? What ethnic or religious traditions encouraged or stifled other types of expression?

She also advocates for considering what she calls the Pain / Energy Price Index when deciding whether or not to do desired activities that are affected by the illness. The chart above uses some common activities as examples of times when a person with a chronic illness might have to leverage available energy and accommodate inevitable after-effects.

WE ARE LUCKY TO HAVE CAUGHT DR. STEINER'S EAR FOR A FEW QUESTIONS:

Q There is research that points to significant rates of new depression and worsened existing emotional/mental conditions post-surgery in our community, and yet psychological wellness doesn't seem to be a major part of the care plan for most patients. It can be really difficult to be proactive when you're experiencing depression. Any tips on good ways to get past the self-barricade to seek help?

A This is such an important question! Too often doctors and families focus on the medical issues, and don't know how to address the emotional effects of the medical issues. Remember the phrase "psychosomatic" – often used to discount one's medical reality? I prefer to think in terms of having any chronic medical condition as somatopsychic. In other words, if you have a medical condition, heart problem, etc., there are inevitable emotional side effects that are important to acknowledge. I think about living with chronic illness or pain as living over an underground river of sadness, or grief. Most of the time the losses and sadness are underground. When set-backs, flares, or new medical issues arise, or other stresses, losses and traumas happen, those emotions lurking underground may surge up and be disturbing. It can help to know that there will be times when you lose your emotional equilibrium. If therapy, journaling or other coping

continued

tools aren't in your toolkit, consider talking to a trusted friend so you don't have to be alone during challenging times.

Q You warn of the misuse and abuse of "positive thinking" and the power of words. Can you explain further?

A While it is important in many ways to be positive and to invest in self-care, too often well-intentioned comments from loved ones can, unintentionally, be hurtful. For example, if someone says, "You just need to try harder," you are likely to feel blamed for having the illness. Barbara Ehrenreich addresses the downsides of positive thinking in her important, provocative book, *Bright-sided: How the Relentless Promotion of Positive Thinking Has Undermined America*.

Q The poem you quote on your website, "Choice + Chance = Change", is a powerful way of seeing self-help and self-advocacy, but not everyone can look at it and imagine enacting it for themselves. Is it ok to allow oneself to stay in a low for a period of time when the effort to do the opposite feels like it's doing more harm than good?

A Definitely! As Dr. LeMaistre so beautifully describes, intermittent depression is a normal response to a chronic condition. Set-backs, flares, and other life stresses and losses are all times that are likely to create more depression. Feeling depressed, while normal at times, can be made less painful by talking about it with a psychotherapist, a clergyperson, in a group, with trusted friends, or through freewriting. Exercise, as appropriate for you, has been shown to help with depression, as has mindfulness meditation. Finding ways to make room in your life for the rollercoaster of your chronic condition, without being defined by your medical diagnosis, is a large, yet important project.

Q Any warning signs to look for that the stay is starting to be too long?

A Depression can interfere with normal functioning – in relationships, work, and family life. Without help, it can lead to thoughts of hurting oneself or others. Thoughts and comments about not wanting to live need to be taken seriously, not discounted as "just trying to get attention." Instead, most often such comments mean that the person is in significant emotional pain and needs professional help. As the American Psychological Association's Help Center (apa.org/topics/depression/index.aspx) says, "Depression is more than just sadness. People with depression may experience a lack of interest and pleasure in daily activities, significant weight loss or gain, insomnia or excessive sleeping, lack of energy, inability to concentrate, feelings of worthlessness or excessive guilt and recurrent thoughts of death or suicide." Withdrawal, persistent, intense feelings of sadness, and noticeable changes in motivation are warning signs of depression.

Another important warning sign is if you become obsessed with negative thoughts. If they persist, it is important to tell your physician(s), especially since, as I mention in the depression checklist that follows, depression can be a side effect of medications and can become life-threatening. Some research indicates that pathways in the brain get created if clinical depression goes untreated for more than six weeks. If you aren't getting any breaks in feeling depressed, if you get stuck in feeling that all you are is your disease, those are times when it is best to get professional help.

I remember being impressed by a candid radio interview with Maya Angelou who famously said, *"I've learned that no matter what happens, or how bad it seems today, life does go on, and it will be better tomorrow."* In that interview she mentioned considering suicide and being told that she could always chose to end her life another day, but that if she made that decision on that day she wouldn't be here to see how things got better in days ahead. She spoke of her gratitude for having chosen life at a time when she felt she had lost all hope.

As a reminder, The National Suicide Prevention Lifeline can be reached at 1-800-273-8255 or online at suicidepreventionlifeline.org. Their online chat at suicidepreventionlifeline.org/chat is worth having easy access to.

Q We've lost fellow Cushing's patients to suicide this year. Your lists of symptoms of and facts about depression are at the end of this article, but are there any things we can be alert to in other people who may be suffering and need help? It's hard to see through a great actor's or actress' façade of wellness, but there must be clues. We need to look out for each other too.

A First, please accept my deepest condolences to you and your community! Since there are times when it helps to pretend to be fine, it can become easy to "pass" and hide one's emotional pain. One side effect of depression is that it gets in the way of thinking clearly. Feeling hopeless and concerns about being a burden can increase feelings of worthlessness that feed suicidal thoughts. I address some of these issues in my article, "Tool Kit for Families Living with Chronic Medical Illness" (drsteiner.com/artpub_articles_toolkitfamilies.html). About how you can look out for each other, that is a big question, worth more attention than just a few sentences here can address. Having a therapist give a talk about this important topic, and/or write an article about it, is worth considering. For now, consider talking with each other about your feelings and beliefs about suicide, and make one-on-one agreements with each other that if things get that bad that you will let each other know, and reach out for help. Two resources worth having easy access to are:

- **Befrienders Worldwide,** an organization of providers of emotional support and suicide prevention (befrienders.org)
- **The National Suicide Prevention Lifeline,** contacts earlier in the article, "provides free and confidential emotional support to people in suicidal crisis or emotional distress 24 hours a

day, 7 days a week, across the United States. The Lifeline is comprised of a national network of over 150 local crisis centers, combining custom local care and resources with national standards and best practices."

Q What are you working on right now?

A I will be revising the Pain/Energy Price Index for *The Rollercoaster of Chronic Illness: How to Add Joy to the Ride,* have a chapter about the Art of Complaining Without Clearing the Room, and am expanding the section currently on my website about nicknaming your illness. I would love to have your readers make suggestions for examples of activities they enjoy which are costly physically for the revision of the Pain/Energy Price Index, and have them be beta readers when the book is ready.

SYMPTOMS OF DEPRESSION

- Feelings of extreme sadness or despair for at least two weeks or longer
- Persistent sad, anxious, or "empty" mood
- Feelings of hopelessness, pessimism
- Increased use of drugs and/or alcohol
- Social withdrawal, isolation
- Major change in self esteem, deterioration in hygiene habits
- Feelings of guilt, self-condemnation
- Anger, worthlessness, helplessness
- Loss of interest or pleasure in hobbies and activities that were once enjoyed, including sex
- Decreased energy, fatigue, being "slowed down"
- Difficulty concentrating, remembering, making simple decisions
- Insomnia, early-morning awakening, or oversleeping
- Appetite and/or weight loss or overeating and weight gain, not medication related
- Thoughts of death or suicide, talk of harming self or others, suicide attempts
- Restlessness, irritability

FACTS ABOUT DEPRESSION

- Depressed individuals tend to feel helpless and hopeless and to blame themselves for having these feelings. This cycle often interferes with asking for help.
- There are many forms of depression. Some people experience a few symptoms, some many. Severity of symptoms varies with individuals and also varies over time.
- People who are depressed may become overwhelmed and exhausted and stop participating in certain everyday activities altogether. They may withdraw from family and friends and have difficulty with routine activities.
- Having one episode of depression greatly increases the risk of having another episode. Some research indicates that ongoing psychotherapy may lessen the chance of future episodes or reduce their intensity.
- Research has shown that the combination of psychotherapy and antidepressant medication reduces life-impairing problems of depression.
- Chronically ill patients are at higher risk for depressive reactions, hence it is important that they report changes in mood to their physicians.

Reminder: Depression can be a symptom of Cushing's and a side effect of certain medications. Be sure to notify your physicians if you have significant mood changes.

Editor's Note: *Many thanks to Dr. Ann Steiner for her permission to use the Pain / Energy Price Index and to print the above Symptoms of and Facts About Depression. Please visit her website at DrSteiner.com for more resources, to share your input, or to contact her directly.*

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

CSRF Finances: FY 2017

By Elissa Kline, Treasurer

We are pleased to share our annual financial report. This is the third year we have prepared a financial report for the newsletter. Compared with 2016, both income and expenses were greater. Our income in 2016 was $45,279, and in 2017 it was $50,953. Our expenses in 2016 were $30,861, and in 2017, $71,578. Surpluses from past years enabled us to spend beyond our income in 2017 – keep reading to see what we spent this on.

Our largest source of income continued to be grants, followed by donations, and then membership. Our largest expense in 2017 was the Patient Education Day, followed by our newsletter. Meeting attendance, where we staff display tables and attend sessions to learn the latest medical developments, remains a large annual expense. We participated in an advertising campaign featuring a page in an insert appearing in four markets of USA Today, which was also distributed to several conferences and was available online. The goal of this campaign was to raise awareness of Cushing's to a very broad audience.

This year we are beginning an ongoing outreach campaign to endocrinologists across the US. We hope this raises awareness amongst practitioners who don't just focus on rare endocrine disorders, as many Cushing's patients are initially diagnosed with diabetes. While we will not hold a Patient Information Day in 2018, we are in the beginning stages of organizing one for 2019. We've also greatly reduced the cost of maintaining the website and mailing the newsletter; we will put this money to work on other projects.

Cushing's Patient Pamphlets

Pamphlets include *Understanding Cushing's, Diagnostic Testing, Recovery, Prevention and Treatment of Adrenal Insufficiency,* and *Why Replacement Medications are Needed.*

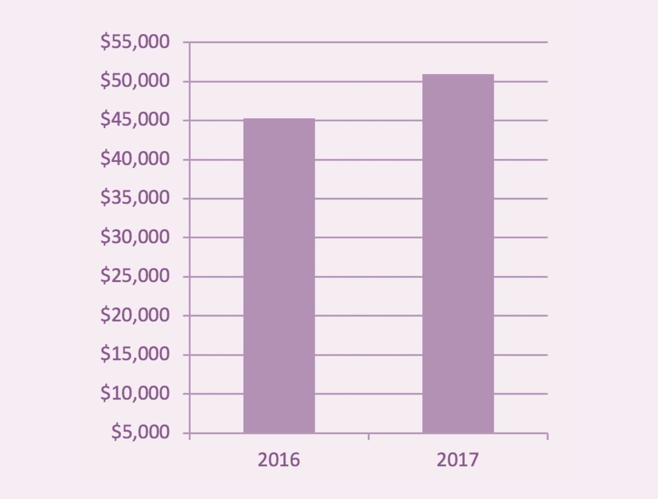
ENGLISH TO SPANISH TRANSLATION

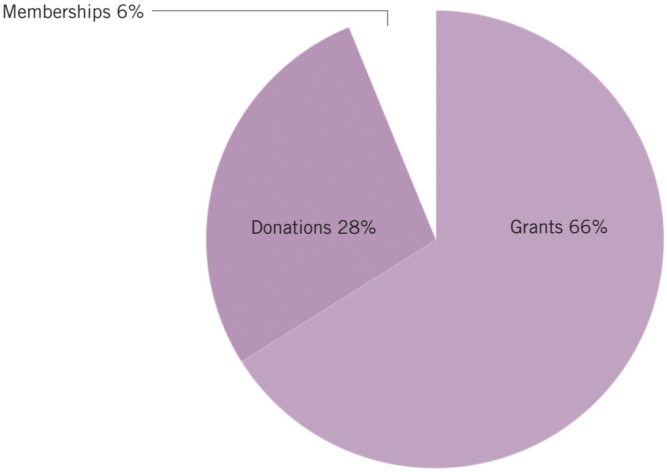
Thanks to the efforts of Dr. Marta Araujo Castro, an endocrinologist at the Puerta de Hierro's Hospital, in Madrid, Spain, the Cushing's Patient Pamphlets have been translated into Spanish and will be posted to our website shortly!

ENGLISH TO FRENCH TRANSLATION

Thanks to the joint efforts of Anne Marie Bergevin and Dr. Andre Lacroix, French versions of some pamphlets have been posted to our website.

INCOME

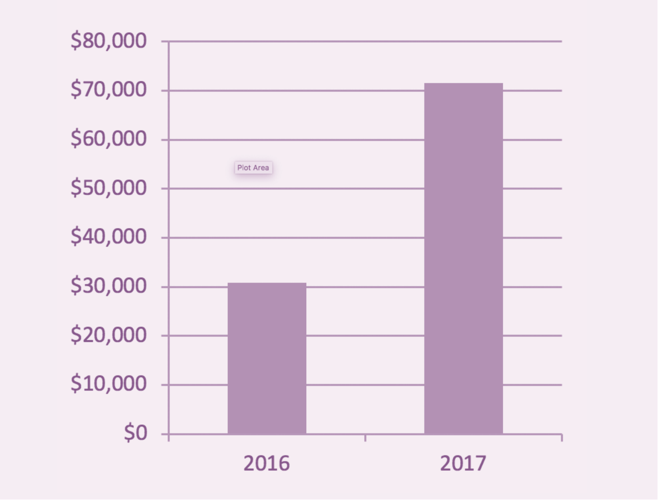


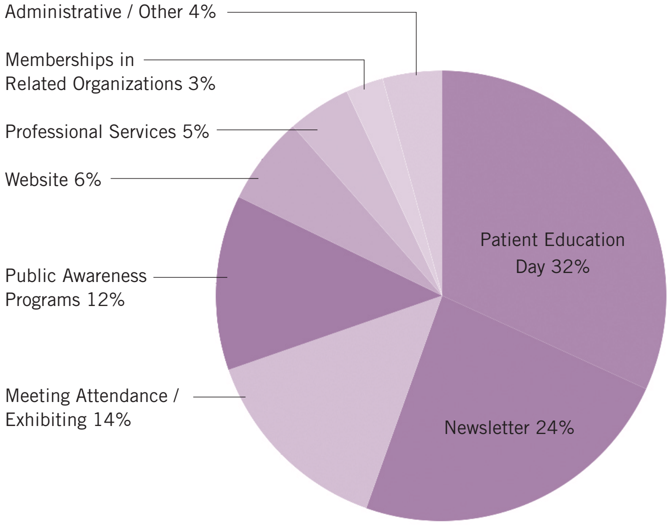


INCOME

Grants	$33,675
Donations	$14,123
Memberships	$3,150
Interest	$5
Grand Total	**$50,953**

EXPENSES





EXPENSES	
Patient Education Days	$22,782
Newsletter	$16,917
Meeting Attendance: Exhibiting	$10,173
Public Awareness Programs	$8,960
Website	$4,518
Professional Services	$3,248
Memberships in related organizations	$1,924
Other	$1,514
Fundraising	$465
Printing / Office Supplies	$667
Virtual Patient Ed. Meetings	$274
Taxes and Government Fees	$135
Grand Total	**$71,578**

Thank you for your support!

DONORS: $500 – $2,500

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Doctors' Answers

Q Can I develop exogenous Cushing's from steroid use that stopped several years ago? I had a series of injections between 2010-2014 and this year I've been noticing some symptoms I suspect are Cushing's.

A The effects of exogenous glucocorticoids can be subtle at first and are generally slowly progressive. It typically takes several months for such effects to become noticeable. In addition, some of these effects can persist for a long time after glucocorticoid use has ended. On the other hand, it would be unusual to observe manifestations of Cushing's beginning to develop several years after glucocorticoid use has ended. *(answer by Dr. Nicholas Tritos, Massachusetts General Hospital, Boston, MA)*

Steroid (glucocorticoid) containing compounds of any type including injections, oral medications, skin creams, certain asthma inhalers, even some hemorrhoid ointments, may all lead to exogenous Cushing's. The dose of the steroid and the duration of use are all important factors, but people differ as to their response. Although the clinical effects can persist after the steroid is stopped, new symptoms of Cushing's that develop years after steroids are all discontinued can't be attributable to steroid use years ago. The best way to see if a patient has Cushing's is for them to see an endocrinologist so that screening tests can be done if appropriate for the patient after a full evaluation including a history and physical examination. *(answer by Dr. Anne Klibanski, Massachusetts General Hospital, Boston, MA)*

Q I've read that lots of common medicines and treatments can raise or lower cortisol. There's not much mention of the quantity of these meds that affect cortisol though. Xanax and codeine lower, for example, and Zoloft, Ritalin, St. John's Wort, alcohol, and even marijuana raise cortisol. Growth and thyroid hormones are reported to lower cortisol. If I take one or more of these substances or others that are listed as affecting cortisol, at what point should I be concerned that they could be affecting my testing results or cortisol levels before or after surgery?

A Although several medications have been reported to either raise or lower cortisol after acute administration, there is a more limited number of pharmacologic agents that are known to influence the results of diagnostic tests. For example, regular use of opioids, especially long acting opioids, can lower cortisol levels, leading to biochemical evidence of adrenal insufficiency (sometimes with associated symptoms of hypoadrenalism). On the other hand, consumption of alcohol in excess is well known to raise cortisol levels and lead to falsely positive results on many tests used to diagnose Cushing's. Of course, glucocorticoid use in any form can confound the interpretation of diagnostic tests for Cushing's and needs to be carefully considered in every case. *(answer by Dr. Nicholas Tritos)*

Q If you have been in practice for 15 years or more, what changes have you seen in the Cushing's medical community regarding treatment, medical therapies, theories on causes, etc.? Before we had any medications available, what did Cushing's patients do if surgery and/or radiation didn't work or they weren't a candidate for either?

A In the 1960s and 1970s bilateral adrenalectomy was often used to treat Cushing's disease. With the refinement of pituitary microsurgery, bilateral adrenalectomy has become much less popular because of its obvious shortcomings (adrenal insufficiency, risk of Nelson's syndrome). Although there are more medications available nowadays, the role of medical therapy remains adjunctive in patients with Cushing's disease (for example, it is often used as a "bridge" until radiation therapy takes effect in patients who cannot be cured by pituitary surgery).

In the past, it was debated whether Cushing's disease is caused by a pituitary adenoma or hypothalamic dysfunction. With the recognition of monoclonal pituitary adenomas in patients undergoing pituitary microsurgery, it has become clear that (generally benign) pituitary tumors underlie Cushing's disease. More recent discoveries, including the detection of *USP8* gene mutations in a substantial proportion of these tumors, have begun shedding more light on the molecular underpinnings of this condition. *(answer by Dr. Nicholas Tritos)*

Research Summaries

We recently came across the following two cortisol-related case reports in the American Association for Clinical Endocrinologists' *Clinical Case Reports* publication. Case reports seem to play a unique role in the scientific world – they cover instances where something interesting or unexpected happened that isn't part of the common understanding of a particular disease. The goal is to make other researchers aware that this new thing has happened, and maybe it will happen again. There might be useful information to be gleaned from these reports even if the scope of the discovery is only a single person.

On the other hand, this singularity is also the reason that these reports have a limited, specific usefulness to researchers. Research articles, in contrast, are full reports of data from organized clinical trials and studies that use multiple subjects and include methods and results, not just an introduction, discussion, and conclusion.

Since we patients are used to hearing about how uncommon our condition is, and we are frequently the only patient at least one of our doctors has ever seen…we embrace the uniqueness of these case reports! It is not hard for us to imagine learning of these patients through support channels and considering their cases as maybe not so rare as is being described. We appreciate the persistence exhibited by these doctors in their pursuit of solutions to help their patients stop suffering. Please use the title or DOI code to search for the full case report online if the summary interests you.

A Case of Cushing Syndrome Successfully Treated with Superselective Adrenal Arterial Embolization of an Adrenocortical Adenoma with a 6-Month Follow-Up, Ahmad S, Ong R, Malhotra A, Siskin G, Shawa, H. *AACE Clinical Case Reports.* 2018 July/August 4;4:e275-e277. doi: 10.4158/accr-2017-0012

In this case, a 35 year old morbidly obese woman with Cushing's Syndrome (adrenal source) presented at the hospital with septic shock due to necrotic pancreatitis (tissue dies off due to severe infection and then becomes infected itself) and an abscess in the pancreatic tissue. A CT scan revealed a large adenoma on the left adrenal gland and the patient was scheduled for an outpatient adrenalectomy.

Before that could happen, the patient ended up back in the hospital with septic shock and multiple organ failure. She was started on ketoconazole but switched to metyrapone because the proton-pump inhibitor (PPI) she was taking reduced the effectiveness of the ketoconazole (OTC examples of PPIs include Prilosec and Prevacid). She had open surgery to attempt to remove the tumor, but doctors could not reach her adrenal gland due to inflammation and scar tissue. Instead they decided to cut off the blood flow to the tumor via "superselective embolizaton", which is done under conscious sedation and local anesthesia in the radiology department.

After the embolization, the patient's cortisol levels dropped, metyrapone was discontinued, and hydrocortisone replacement commenced. She lost 80 lbs and most of the cushingoid features over three months. Four months after the procedure, workups indicated that her cortisol levels were still low after withholding hydrocortisone therapy for 24 hours, so she resumed taking it after testing. At that four month mark a CT scan also showed a remarkable reduction in size of the adenoma – from 3.5x2.7cm before the embolization to 2.0x2.1cm months later.

This story has an unfortunate ending: six months after the procedure, the patient arrived at the hospital with an "altered mental status" and was found to have had a massive hemorrhagic stroke and subsequently passed away.

Adrenal Suppression Secondary to Interaction of Combined Inhaled Corticosteroid and Antifungal Agent, Pimentel J, Kapadia C, Newbern D, Shaibi G. *AACE Clinical Case Reports.* 2018 July/August 4;4:e305-e308. doi: 10.4158/accr-2017-0187

In this case, a nine year old girl came to the endocrinologist to be evaluated for low bone mineral density because she had a recurring fracture in her right knee. She was already taking calcium and Vitamin D supplements and was not a candidate for bisphosphonate (bone density protective) therapy, so she was sent home and asked to come back for a repeat bone scan in six months.

This patient had Hyper IgE Syndrome, a rare primary immunodeficiency disease frequently characterized by eczema, staph abscess infections of the skin, and lung infections. She had had fungal meningitis and lung lesions that led to removal of the middle lobe of her right lung around age six. She had been taking prednisone for a fungal lung infection but had stopped that about a year before she was seen by the endocrinologist. She had also been taking inhaled fluticasone (Flovent) twice a day for several years, and was on a maintenance dose of the antifungal medicine posaconazole.

About five months after the initial endocrine visit, the patient's mother halved her dose of fluticasone because her daughter's breathing had improved. Not long after that, the patient began to lose her hair and complained of fatigue. She also had a puffiness to her face, so her mother took her to the pediatrician who ran panels for electrolytes and thyroid function, which were normal, and a morning cortisol that was almost non-existent. The patient was called back to the endocrinologist the next day and produced extremely low results on the ACTH stimulation test.

Based on clinical presentation, the doctors suspected adrenal suppression secondary to medication use. They postulated that the interaction between inhaled fluticasone and posaconazole (which can delay fluticasone metabolism) gave rise to the Cushingoid features and adrenal suppression in this patient. The take home message would be to avoid such drug combinations, if possible. The patient didn't have other signs of adrenal crisis, but due to her fatigue the doctors felt it warranted therapy with hydrocortisone replacement. Over the next seven months the patient was weaned off the hydrocortisone and also stopped taking the fluticasone. A follow up ACTH stimulation test showed resolution of the adrenal suppression. The patient's Cushingoid features also resolved and her growth got back on the charts.

On-line Tools for Symptom Tracking

Symptom tracking can be useful for gauging your recovery or determining when to test if cyclic Cushing's is suspected. A symptom tracking application from Corcept, maker of Korlym, is available here: *www.cushingsconnection.com*

Caregiving & Cushing's

By Dawn Herring

You may have never thought of yourself as a caregiver, but there's a good chance you provide caregiving if you support a Cushing's patient in any way. One of the challenges for society in supporting caregivers is that caregivers rarely self-identify. They feel they are just doing what is necessary. But caregivers need support.

Being a caregiver can be very rewarding. It can also come with some profound challenges. In this article I am going to outline some of these challenges and strategies for self-care.

I write this article from two perspectives. The first is as a Cushing's survivor. The second is as a mental health professional who has worked extensively with veterans and their caregivers; I lead groups and retreats and speak publically at caregiver symposiums for those caring for our wounded, ill and injured veterans. Veterans, like us Cushing's patients, experience chronic pain, memory loss, trauma symptoms, poor sleep, depressed and anxious mood, irritability, and sometimes even suicidal thoughts. While the origin of their symptoms is drastically different, the road to recovery has some striking similarities. Throughout the journey, we all need a support system, veterans and Cushing's patients alike.

Veteran caregivers, much like patient caregivers, can be frustrated with the system and confused by the complexity of navigating numerous health care providers and diagnoses. Many caregivers suffer from compassion fatigue, symptoms of depression, confusion, frustration, and a profound sense of powerlessness. As I have written in the past, an impactful support system is most helpful when it is comprised of those we love and trust who bring us comfort; they see and hear us accurately and still believe in us. That caring, however, comes at a cost. This article is for those who care for Cushing's patients.

Rarely does a marriage start out with the intention of caregiving. Sure, we realize on some level that maybe when we are old – very, very old – we will need to care for one another. Likewise, we never plan to have our child or any of our friends become sick. Those who support Cushing's patients and survivors in their journeys toward diagnosis, treatment, and healing know that the road is not paved. In fact, it is often filled with switch backs, narrow lanes, apparent dead ends, forks in the road, and lots of night driving. For caregivers, this road can be very lonely and confusing. It is filled with an overwhelming sense of powerlessness and fraught with frustration and uncertainty.

The emotional and physical toll of caregiving is challenging to quantify. Research has begun to do so for certain populations. While we do not have hard statistics on the impact of caregiving for Cushing's patients, we can fairly easily extrapolate from existing data that there is an impact. The impact may be relational, physical, spiritual, and mental. As a caregiver, you may find yourself feeling a lack of energy or interest in doing things that used to give you pleasure. You may also feel sad or guilty, as though you are somehow failing your loved one by not doing enough. Alternately, a sense of disconnection may result, and with it, guilt for feeling disconnected. Resentment can arise, followed by guilt for having resentment. Depending upon the relationship, various losses may be incurred. If the relationship is a partnership, intimacy is likely to be compromised. This can result in a multitude of confusing feelings for both parties. At times, relationships have not survived the journey. What can be done?

1. **Talk to your loved one about your feelings.** It is a misnomer that talking about feelings will burden your loved one. The alternative is a gradual numbing and/or resentment in the relationship. Chronic numbing can result in the death of that relationship. Talking, no matter how challenging, creates connection. For assistance on how to do this effectively, watch Brene Brown's 3 minute YouTube video "On Empathy" at youtu.be/1Evwgu369Jw.
2. **Remain nonjudgmental** of both your emotional experience of this process and your loved one's experience. The layer of self-judgment or judgment of the other is a waste of both energy and time. Don't do either. Instead, do #3.
3. **Make your loved one an expert** in their experience. "I don't know your experience. Please tell me. How can I support? What do you need? Here is my experience as your caretaker."
4. Have **realistic expectations** of yourself and your loved one. You are only one person. Remember that you don't have to fix it, just listen.
5. **Talk to your doctor** if you feel a growing sense of depressed or sad mood. A referral to a counselor may assist in managing the feelings that come up. Guilt and resentment are normal. Changes in eating or drinking alcohol may occur.
6. Remember **daily self-care,** no matter how little is essential to keeping resentment at bay, i.e. eat healthy, exercise, take time for yourself, take a bath, take a class, pray, meditate.
7. Remember to engage in your **passionate pursuits** when possible. These are things that give you a sense of purpose and meaning. They also give you joy and a way to pass time. Examples include but certainly are not limited to dancing, painting, working on the car, working out, golfing, bowling, fishing, quilting, cooking, baking, and woodworking.
8. **Connect with others.** Have coffee with friends. Join a support group in person or on line with other caregivers. You do not have to do this alone. As Brené Brown says, "Share with people who have earned the right to hear your story."
9. Stay connected with the CSRF network, and seek out credible and credentialed scientific information. Learn all you can about Cushing's through **legitimate means.** (I don't recommend Google)
10. **Have hope.** This is a process, not an event. There is healing taking place. In the meantime, your job is to take care of yourself first. This is the best gift you can give your family member or loved one and yourself.

If you want more information, please feel free to read earlier articles on the CSRF website to include:

- *Coping with an Unknown Outcome: Ambiguous Loss*
- *Coping with Embitterment to Improve Quality of Life*
- *Sex and Cushing's*
- *Managing Stress Through Cushing's*

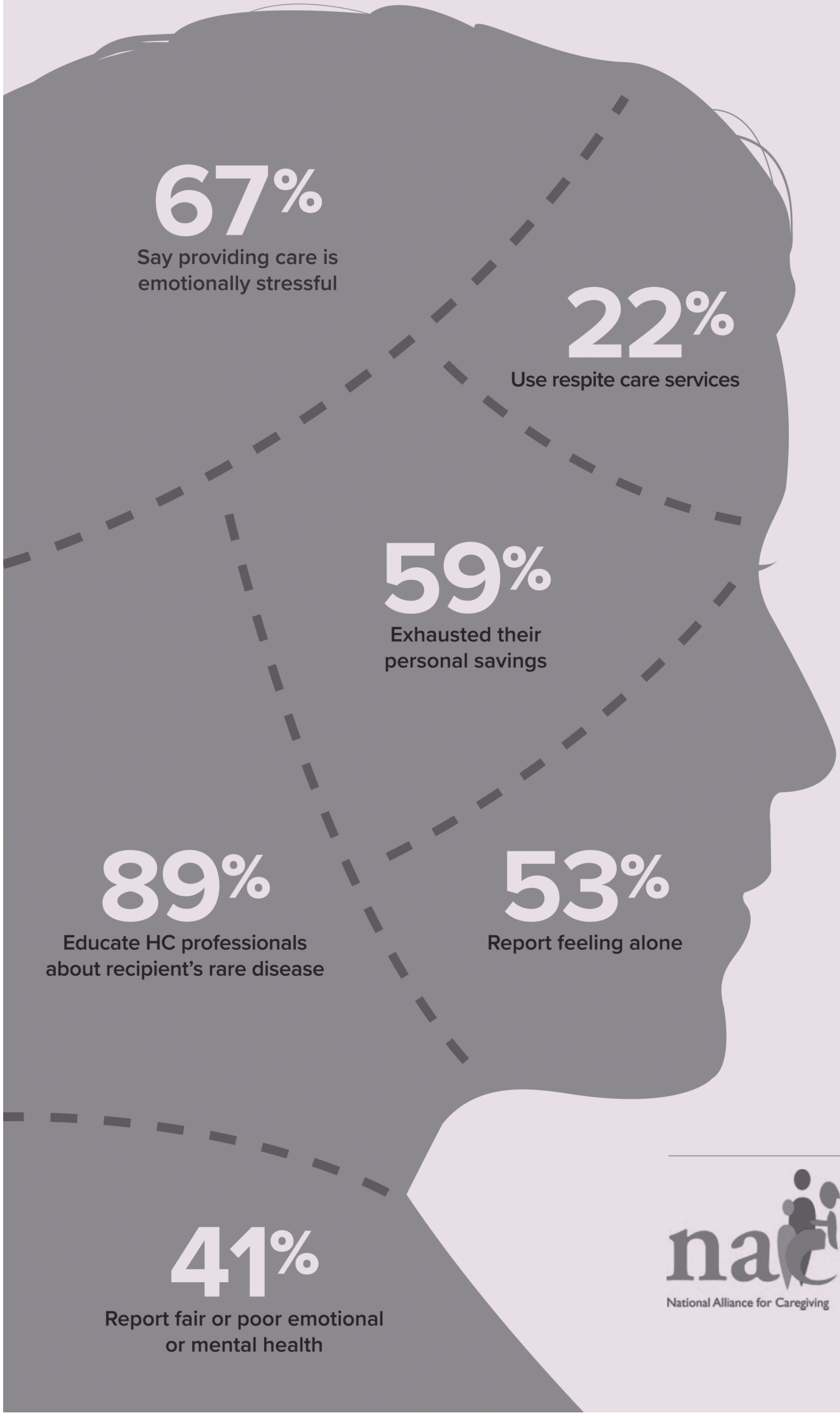
While these were created for Cushing's patients, the information they provide will benefit caregivers as well. The "Managing Stress Through Cushing's" article has key ingredients to assist anyone in improving their stress management skills. Also, the webinar on Quality of Life on the CSRF website may be useful as well.

On the flip side, we know that those caring for others can experience a profound sense of meaning and purpose, that caregiving can actually lengthen life span. Because we are hard wired to attach to one another, to need to be in close proximity to one another and have purpose and meaning in life, caregiving can fulfill these needs. It seems that it is not the caregiving alone that is stressful but the meaning we give it that can be either stress-producing or life-enhancing. Kelly McGonigal discusses this in her TED talk, "How to make stress your friend," at youtu.be/RcGyVTAoXEU. I encourage everyone interested in resilience to watch this 15 minute video.

In sum, caregiving can be both rewarding and challenging. The concept of self-identifying as a caregiver can also be important, as it validates the inherent struggles and unique challenges therein and provides an avenue to better understand one's experience. This under-

continued

PORTRAIT OF A RARE CAREGIVER



67%
Say providing care is emotionally stressful

22%
Use respite care services

59%
Exhausted their personal savings

89%
Educate HC professionals about recipient's rare disease

53%
Report feeling alone

41%
Report fair or poor emotional or mental health

59%
Receive help from at least one other unpaid caregiver

29%
Have plans in place for their care recipient's future care

24%
Report unpaid care from at least one youth under age 18

10%
Are students who often struggle with school responsibilities

THE RIPPLE EFFECT

The ripple effect of rare caregiving extends beyond day-to-day tasks of providing care and creates the need for others in the family to pitch in.

National Alliance for Caregiving

IN PARTNERSHIP WITH

Global Genes
Allies in Rare Disease

www.caregiving.org
www.globalgenes.org

Rare Disease Caregiving in America, February 2018
Get the study at: www.caregiving.org/rare

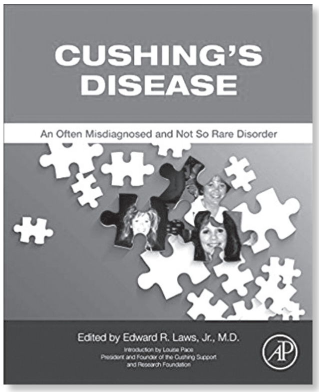
standing can improve conscious coping to prevent compassion fatigue and maintain robust self-care. We humans will always heal better in the presence of another. So please continue to care for yourself, daily, in little ways. *Be kind* to yourself, be *self-compassionate,* be *creative,* and be *forgiving.* Thank you for all you do every day to support the healing of your loved one.

"To keep a lamp burning, we have to keep putting oil in it."
— Mother Theresa

Editor's Note: *The graphic included with this article was shared with permission from the National Alliance for Caregiving (NAC). While caregivers of Cushing's patients have a very different experience than caregivers of some other diseases, these statistics hold true for everyone.*

NAC organized with Global Genes in September of 2017 to run a research study collecting data about rare disease caregivers. Within six months they had produced an impressive 90 page document titled Rare Disease Caregiving in America after receiving responses from over 1400 rare disease patient caregivers. You can find this document plus the questionnaire they used and the full list of rare diseases that were represented at caregiving.org/rare.

Cushing's Disease: An Often Misdiagnosed and Not So Rare Disorder



Edited by E. Laws, Jr., M.D., F.A.C.S., Professor of Neurosurgery, Harvard Medical School, Director – Neuro-Endocrine / Pituitary Program, Brigham and Women's Hospital, Boston, with an introduction by Louise Pace, Founder and President of the Cushing's Support and Research Foundation.

This comprehensive guide to Cushing's disease describes the functions of pituitary, adrenal and other hormones, lists the typical and atypical symptoms of Cushing's disease and its subtypes, outlines the causes of elevated cortisol and explains how clinicians can test for, diagnose and treat Cushing's disease. Physicians will find this concise book detailed, thorough and well-referenced. Patients will also find clear and helpful information in this important book. *Published in 2017 by Elsevier Inc – an excellent resource for physicians (and patients)!*

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I hate alligators. Alligators are terrifying and rather vicious animals. These large and menacing reptiles are fairly easy to spot in my native Louisiana. They are glorified in every way, on every restaurant menu and tourist attraction from Bourbon Street to Jefferson Square. If you go to the Audubon Aquarium, you can even see the extremely rare albino alligator. The description at the aquarium says the albino alligator is one of the rarest animals in the world, extremely dangerous, but unable to survive in the wild. I can empathize with the albino alligator. My journey with Cushing's Disease has left me feeling like a rare being. The beauty in my journey comes from finding a community of these rare beings and seeing what they have been through and knowing there is comfort in suffering. There is comfort in knowing that, while rare, you are not alone.

Upon reflection, my life has been filled with a myriad of symptoms that sent me to several doctors and a confusing chain of "wrong answers." My Cushing's journey began in earnest over 10 years ago. I was living in San Francisco, with a great deal of responsibility in my young life. I was in my early 20s, managing a large global account for my company, and feeling hopelessly unprepared and overwhelmed. To the outside eye, even at that time, I looked out of place, like an albino alligator. I was successful but also cracking under the pressure. I suffered my first major manic phase followed by a major depressive episode. This episode was near deadly for me. This low point directed me to a psychiatrist, who diagnosed me with a mental illness. Ten years ago, no one talked about mental illness. It was yet another thing that made me feel rare. Dramatic mood changes are a symptom of Cushing's. Unbeknownst to me, I had other Cushing's symptoms at the time that I did not recognize. I had a fully rounded face (moon face), irritability, easy bruising, migraines, etc. Because the prevailing symptoms were mood changes, explained by mental illness, I never gave merit to the others. Eventually, I realized that fighting this on my own was tearing me apart and I needed the loving support of my family. I called my brother, bought him a plane ticket to the West Coast and we packed up my car and drove cross-country to Atlanta.

Fast forward from 2009 to 2015. I had close to eight years of successfully managing my mental illness and feeling like a healthy, upstanding professional again. Being near my family gave me the comfort and watchful eyes to help me navigate through the ups and downs. Little did I know, in my comfort, a perfect storm was brewing that would strip away any protection I had from the unforgiving wilderness of life. I was still the albino alligator; I just found a great disguise and support system.

In 2015 I experienced a major manic episode, a mixed mood episode, and a major depressive episode all in the course of a couple of weeks. This again proved almost fatal. Something had to give. Was I destined to experience this for the rest of my life, or was this something out of the ordinary? I was still unaware of Cushing's. On top of the mood swings were weight gain and elevated blood pressure. Frustrated and confused, I went to the Mayo Clinic in Minnesota. Perhaps seeing a battery of doctors could make sense of all these disparate symptoms I was experiencing. I could no longer chalk it all up to a mood disorder.

Feeling exposed and desperate for some sense of cover, I sincerely thought going to the Mayo Clinic would make sense of all the horrible health effects I was experiencing. I saw many great doctors but unfortunately, these seemingly random symptoms I was experiencing just didn't fit the coordinated puzzle they were used to seeing. I was rare and I didn't fit into what was easily classifiable. "No one understands yourself more than you" my mother would say, and while true, I started to wonder if this was all in my head. Was I a hypochondriac?

I became desperate to change my lifestyle in hopes of seeing a positive effect. I exercised more and ate better because I can control those things. After returning from the diagnostic center, I became hyper focused on being an athlete. My family was a great support. My big brother, Warren, would go running with me regularly and my sister, Emily, did a triathlon with me in Chicago. All the intense exercise and sport amounted to no difference in my body. No matter what I did, I just could not lose weight. Not only could I not lose weight, but also I was gaining it at a rapid pace. I tried vegetarian and vegan diets, but the only way I could lose weight was just stop eating. I tried to blame the weight gain on all the traveling I was doing for work and that I was eating out a lot. These were all perfectly normal rationalizations IF I was perfectly normal.

After a year of trying, I gave up. The diet and exercise felt like me trying to be something I wasn't. I am not a gazelle. I am an albino alligator and a rather large one at that! In desperation, I started eating whatever I wanted. I gained more than 100lbs in 18 months. Little did I know then, my weight gain was a classic sign of Cushing's disease. Rather than hide my problems or change my physical makeup, I embraced them in hopes that mentally I could accept what I was and at least find happiness in the symptoms.

Pride and ego are strong parts of every person's personality, but the human body does not care if you feel empowered about your condition or adamant about who you are as a person. You can embrace weight gain in your mind, but your heart and brain could care less. I was not only gaining weight but my mental armor was doing nothing to protect against the rising blood pressure, bloat, bouts of sleeplessness, acid reflux and decreasing energy. I was tired all the time. Again, I blamed that on travelling. The different time zones, the long hours, the red eye flights.

I knew for my health I had to do something. I researched gastric bypass. If my body would not bend to lifestyle changes, then it was time to change my body physically in order to have a chance at survival. Unfortunately, my insurance would not pay for the surgery, but

Zimbabwe, 2015.

On the road to recovery, Fall 2018

> **"Little did I know, in my comfort, a perfect storm was brewing that would strip away any protection I had from the unforgiving wilderness of life."**

I thought it was my only option. I spent a small fortune in hopes that I could become a different person. I would have a Roll Royce of stomachs and in turn, the prestige would benefit the rest of my body.

Like buying a Porsche or a Rolex watch, I certainly looked different but it could not hide who I really was. After the surgery, I lost over 90 pounds, but my abdomen remained large. Conversely, my arms and legs became very thin. I had three people within three days ask me if I was pregnant. It was so humiliating. Even though it felt tragic, it was a key factor leading to my Cushing's diagnosis. The round abdomen, but thin arms and legs are classic Cushing's. Even the cosmetic change in my body would not make me a powerful lioness. I was just a distorted albino alligator and it seemed the world could tell.

The after effects of surgery put me through a physical hell. My body instinctively knew a new stomach was not the answer. Weeks later, I developed an ulcer in my duodenum that we thought was from the gastric bypass, but we now know was also because of Cushing's. This ulcer caused me to vomit constantly. For months, I could not keep food down. The lack of nutrition resulted in critically low potassium levels, hospitalizing me for a week. It is an interesting thing to learn in life the people who care about you when you are at your lowest. Through all the earlier trials, I had supportive bosses who allowed me the flexibility to take care of my health. This was the first time I did not. It was devastating.

My blood pressure was sky high, sending me to the ER three times; once on our beach vacation, a response to the previous hell my body went through. On one of those visits, I showed up to the ER with high blood pressure, low potassium, blurred vision and a rash on my neck. I remember one of the doctors leaning up against the wall, perplexed. I could see in his eyes, this is unusual, this is… rare. What seemed obvious and routine, was too much to ignore. I wish I could find that ER doctor and tell him. I want to go back to all the doctors and tell them. Not because I wish they would have figured it out, but I know that if they knew, they would be looking for it in others. I have a current doctor who told me he always says, "I have never met a rare disease, but I am sure it has met me." I hope as doctors learn more about rare diseases, they are on the lookout for them.

My symptoms seemed to multiply overnight. When I was hospitalized for malnutrition I had extremely swollen feet. The doctors didn't pursue this further as they were focused on my malnutrition. My mother, a lifelong ER and cardiac nurse, was worried about renal artery stenosis and took me to a cardiologist. When he ruled it out, he sent me to an endocrinologist.

In addition to physical symptoms, I was having cognition problems too. I would walk into a room and not know which room I was in. I would start a sentence and not be able to finish it because I had already forgotten what I was going to say. This was very frightening. It's hard to explain, but you know you are supposed to know something, but you just don't. Like you are outside of your body screaming at yourself to just "spit it out," but your mind will not form the words. This was possibly the scariest side effect. It got so bad I had to rely on my mother to make decisions for me. She would put my pills into packs for the day/time because I would get confused even on what

continued

to take and when. When we went out to do errands, the tremor in my hands was so prominent that I could not get a credit card out to pay for things. If I tried, I would invariably end up dropping it. I dropped and broke so many things during that time. There really are no words to accurately explain how hard this was for me. I was physically and mentally finished.

My mother, a nurse with more than 30 years of experience, was determined to get to the bottom of this. There had to be an answer. Without her persistence and pushiness, I might still be sitting here today without a diagnosis. It is probably a common story for those with rare diseases; you need an advocate, you need someone who relentlessly pushes until there is an answer. With Cushing's, there are so many seemingly random symptoms that you need someone who sees them holistically to advocate. Had any one of those doctors been with me in my daily life, I know they would have figured it out.

I remember exactly where I was when I found out I had Cushing's. I was on my way to Florida with my family when Dr. Reyes, an Emory (Atlanta, GA) endocrinologist, called me after receiving test results. He is such a kind man, working on a Saturday, he said, "I am so sorry, but this is Cushing's." He said it as if I should be sad, but I was happy! There would be no crocodile tears because now we had something to work with. We had an answer! I was completely oblivious to how much that diagnosis would impact my life. I had no idea how important cortisol was and how complex the endocrine system is. I have learned so much about how our bodies work. I am still amazed at how much the pituitary (the size of a pea) controls in our body.

Cortisol affects everything in our bodies, but because of the complexity of the symptoms many people are not diagnosed for eight years or more. High levels of cortisol put our bodies into "fight or flight" mode, which destroys our bodies. In fight or flight, your body tries to perform only essential functions. Many of Cushing's patients have bad side effects like liver damage, diabetes, lung issues, etc. I lucked out and just got osteoporosis and kyphosis (curvature of the spine). I say "just," but I took a minor fall at Thanksgiving and broke five ribs. I also broke two vertebrae in my back – without even falling. I have the bones of an 80-year-old. One orthopedist described them as "mush!"

Osteoporosis is the "side effect" that has affected my life the most since recovery. I am in physical therapy three times a week and do suffer from a lot of pain. Aquatic therapy has done wonders, but I still do have many days of significant pain. The medicine my doctors recommended was Forteo, the only one on the market that creates new bone rather than strengthening existing bone. Unfortunately this is a relatively new medicine that may cause deformities in children, and there are not enough studies to know how long it stays in your body. For those reasons, carrying my own child is no longer an option for me. Osteoporosis and my broken back have kept me from doing long trips to Africa. I have been going there at least once a year for the past eight years. Not being able to see my kids for almost two years is devastating. There are so many new realities to face when you have Cushing's, now I understand why Dr. Reyes said, "I'm sorry."

Looking back now, I was so blessed. I was diagnosed in September and had surgery in November. God blessed me even more because the world's best pituitary surgeon happens to be in Atlanta at Emory Hospital. Dr. Oyesiku was able to successfully remove my tumor and gave me excellent odds of success. While my recovery has been extremely difficult, I no longer feel like my demise is imminent. As Dr. Oyesiku left my hospital room, he said, "Welcome to your new life." I remember thinking at that time, I didn't want a new life, I wanted my old one back. I can say with confidence that I am happier now than I have ever been. I was successfully rescued from the wild before I could perish. I was the albino alligator that was finally recognized and was going to survive.

Like most alligators, I am pretty headstrong and driven. I usually power through any problem that presents itself. It is how I have survived and thrived. Unfortunately, Cushing's disease is like the genetic mutation of the albino alligator; its symptoms are painfully obvious yet so rare that my disease was hiding in plain sight. I am not sure how long I would have survived in this wilderness of life if I did not advocate for myself and more importantly, let those who care be advocates also. Cushing's Disease erased all my strengths and forced me to rely on the help of others, particularly my family, friends, and others who are still suffering today. I might be an albino alligator, rare and endangered, but at least I am something that will not passively perish. I am far too special to let that happen.

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Editor's Note: To read more about the work Laura does, visit rejoicezimbabwe.com.

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.

Want to be on the CSRF mailing list?

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

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Suggested donation is $30.00 or whatever is best for you. All donations are tax deductible. Please make checks payable to CSRF. Memberships without associated donations will be automatically converted to electronic newsletters in 2019. An annual donation in any amount will trigger a 3-issue print subscription.

Are you a Cushing's patient?

☐ YES ☐ NO

Did you have:

☐ pituitary tumor ☐ adrenal tumor ☐ other

Would you like to discuss publishing your story in a future issue of the newsletter?

☐ YES ☐ NO

What would you like to see addressed in future issues?

____

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Need to talk? Local support groups and contacts

Many of you have expressed interest in local support groups and contacts. If you don't live in one of the following areas, consider starting a group in your area! Email the CSRF if you are interested. In particular, we have an existing group in the Los Angeles / Orange County area without an organizer.

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