Me Tox Pretty

A Story of Iatrogenic Botulism and the Ugly Side of Cosmetic Injections

By Megan McCue

About the Author

Megan McCue is a speech-language pathologist based in California. When she is not with her kids, working, or playing her piano, she can be found prosthelytizing about the harms of cosmetic injections to random strangers in her community.

Get in touch: metoxpretty@gmail.com.

Other Books by the Author

Notox (2025)
Iatrogenic Botulism 101 (2025)

Note(s) from the Author

This story chronicles the first 5-6 months of my illness following botulinum toxin injections. As of November 2025, I consider myself 99% healed. I am still very cautious to avoid triggering foods, stress, and practices that aggravate my nervous system, which has never been exactly the same since my BoNT injections. I still have very ugly hair.

I want you, dear reader, to take care of yourself and be aware of the triggering nature of my story**; I do not recommend reading this if you are currently in the early months of iatrogenic botulism, or in the midst of a relapse.**

I wrote and edited this book in three weeks. Please excuse any punctuation or grammatical errors, and please don't email me about them. I'm a recovering perfectionist and it will just add to my insomnia.

Thank you for your purchase and support.

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Dedication

To my beautiful children, mes raisons d’être who always bring me back to the light during the darkest of days.

And to my gorgeous Maman, whose natural beauty, kindness, and wisdom radiate unapologetically.

Chapter 1 - Dr. Perfect Skin

July 9th, 2024, started out like any other Tuesday for me. I was a mom of three young kids with a full-time job as a speech-language pathologist, so my days always began in a fast and furious manner. That particular morning, my mom was coming over bright and early to watch my 10-month-old, so that I could arrive on time for my 8 AM doctor's appointment.

I was booked for my first ever “Botox” appointment, and was excited to see the results. I had been a loyal patient of this doctor going on nearly two years; she was a primary care doctor who offered "aesthetic" services on the side. We had become friendly over the years, greeting each other with hugs and chatting about our busy lives as working moms. I had initially begun seeing her for microneedling facials, and paid out of pocket for a monthly membership to her practice.

She herself had perfect skin, the kind you see in a magazine but never imagine could exist in real life. She was at least 40 years old but had skin like my baby's, with not a fine line, blemish, or freckle in sight. Her face alone was all the marketing she needed for her services.

At each visit, I would sit patiently for an hour through the procedure, while she poked at my face and provided not-so-subtle criticisms of the sad state my skin was in from 30+ years of sunbathing and emoting.

Did I know that my freckles could be reduced with her new laser product (only $1200!)? Did I know that her $122 night cream could reduce my dark circles? Did I know that I smiled too much with my eyes, and that's why I had so many fine lines around them?

What was her secret to flawless skin?, I asked. For more than 10 years, she had been injecting her face with Botox (from hereon referred to as "BoNT" or "toxin"), a neurotoxic drug whose primary ingredient is botulinum toxin (yes, that lethal bugger that used to wipe out entire villages when consumed from poorly canned food). This drug, she explained, "relaxed" her facial muscles and thus prevented wrinkles from ever forming in the first place.

I had heard of BoNT injectables before, thinking they were something celebrities used to plump their cheeks and lips up to clownish proportions. Turns out, what I thought was BoNT was actually a completely different - yet similarly toxic- product called "filler". BoNT did not plump or fill anything, she explained, rather it simply “froze” muscle movement temporarily for a few months at a time.

I started asking around about BoNT in my social circle, and learned that at least a quarter of the women I knew had received injections at some point. My hairstylist did it religiously, my coworker loved her "tox", and even my own sister had tried it and couldn't wait to do it again once she was done breastfeeding.

I began turning the idea over in my head. The rational side of me knew it was the toxin that causes botulism and thus couldn't possibly be 100% safe when injected into the human body. But the emotional (and, to be honest, narcissistic) side of me saw the amazing results from the product, and was becoming increasingly curious to try it.

I consulted with the medical professional who never failed me, Dr. Google. I began conducting what I thought was thorough and judicious online research regarding the safety of botulinum toxin injections. Overwhelmingly, the information was incredibly positive. No, of course botulism can't happen from such a small amount of toxin, silly! That only happens when an unlicensed or inexperienced injector accidentally "overdoses" you with hundreds of units or “counterfeit Botox”. And anyway, the people most at risk of toxin spread are children and adults who have underlying medical conditions, websites assured me.

Okay, I figured, I should be safe then. I had a very experienced injector who was an MD, I had no underlying health conditions, and I was planning on asking for a tiny amount. The only side effects I could reasonably expect to experience were pain at the injection site and a slight headache for a few hours. It appeared that my only serious health risk in trying BoNT was anaphylaxis, and that was an easily treatable condition.

I hurriedly skimmed over a few articles that popped up warning of the potential the drug had to induce botulism. Oh, those are the unfortunate people who overdosed on the toxin or had underlying medical conditions, I thought to myself.

I booked my appointment.

On July 9th, when I got to the doctor's office, I reiterated to her that I wanted the tiniest amount possible of the toxin in my crow's feet (fine lines around the eyes). I just wanted to try it to see if I liked the results. We ended up deciding I would have Xeomin, another brand of BoNT that is "purified" and does not include additional ingredients, like the original Botox brand. You know, "natural" neurotoxin.

She was ready to inject me with 12 units total (6 on each side) and started on my left eye. I felt a tiny prick and nothing else. That was easy! She came around to my right eye.

Ouch, that one hurt a bit more. A few seconds after the prick, I began feeling very strange. The room started to spin, and I was having difficulty focusing on anything. I felt like I had been punched while drunk. My vision was fine, but the part of my brain responsible for the feeling of "clarity" wasn't working.

"Wow, I feel really weird," I said immediately.

"Oh?" asked Dr. Perfect Skin, "You don't like needles?"

"No, I'm fine with needles," I replied. "But my brain feels weird."

She didn't reply. The room fell silent as she discarded the used needle and I sat there desperately attempting to regain my normal cognitive state. I waited the requisite amount of time to prove I was not allergic to botulinum toxin, paid the $90 fee, and then was dismissed. I was given instructions to not lay down or touch my face. Have a great day!

I made it out to my car in the parking lot. I was due at a patient's house in 20 minutes (I work in the home health department for a local hospital, doing speech and swallowing therapy with patients after they return home from hospital stays). My head felt really, really strange- a mix of brain fog, pressure, and an inability to concentrate on anything. Like I was intoxicated, but without any of the "fun" feelings.

Nevertheless, I got in my car and drove to my first patient's home. I struggled to get through the appointment, feeling foggy-headed; my brain was telling me that I needed to go home, now. I finished up quickly with my patient and got back in my car. I called my boss and told her I was leaving work early due to a headache.

The drive home required immense concentration to focus on the road in front of me and make it through every stop light. I arrived home, and was greeted by my baby and mom.

"I feel so weird," I told my mom as I collapsed onto the couch, "I have a weird headache, mixed with brain fog...almost like I have Covid." I didn't leave the couch for the rest of the morning.

I again consulted Dr Google: "Botox headache". Sure enough, I found plenty of reassuring websites. Headaches after BoNT injections were totally normal. They should go away in 24-72 hours and did not warrant any concern. Phew!

And yet. Two hours later I began having other symptoms. Dizziness and nausea, and a complete inability to think straight and care for my baby. Okay, I wasn't warned of any of this, what was going on? I called Dr. Perfect Skin’s office.

"I feel so strange, like my brain is complete mush. I'm dizzy and nauseous and have head pressure…Is this normal?"

"Yes, of course, totally normal!! You are a very anxious person anyway (I am?), so go make a cup of tea and sit down on your couch and relax."

Okay, I thought, trusting the doctor. Just being anxious, roger that.

The next morning I woke up to clear goo filling up and oozing out of my eyes. Weird, I thought, as I walked over to the mirror. Both of my eyes were bloodshot. My vision was normal once I wiped the goo out, so I wasn't too concerned. Just to be sure, though, I once again called Dr. Perfect Skin and reported my newly bloodshot eyes. Her medical assistant called me back a few hours later to inform me that I had "allergies" (overnight?), and made a point to say that my bloodshot eyes had nothing to do with the toxin injections. Interesting… I'd never had allergies in my life, and had not had bloodshot eyes since smoking weed to impress my super cool, older neighbor in high school.

Back to Dr. Google I went since Dr. Perfect Skin was proving to be completely useless. My "Botox and bloodshot eyes" search found that indeed, bloodshot eyes can happen after injections. Great, just normal small side effects, nothing to be concerned about, I thought.

At this point, I was beginning to realize that Dr. Perfect Skin either knew absolutely nothing about BoNT side effects, or was not willing to admit what she knew about them. It seemed to me her bottom line was to ensure I did not correlate any of my side effects with her injections. I wrote her off then and there, and did not contact her again for two months.

Days passed, and my side effects lingered. I catalogued them in the “Notes” app of my phone at the time so that I wouldn't forget: "Headache, head pressure, brain fog, dizziness, nausea, bloodshot eyes" for the first four days.

Despite the effects lingering for longer than I wanted, I told myself they were totally normal, and that they would pass with time. Little did I know, in the coming days and weeks, an avalanche of symptoms was about to come pouring in and upend life as I knew it.

Chapter 2 - The Panic Period

Before I dive into the “anxiety and panic” phase that unfolded, I need to provide some background information.

I’m a mom of three young kids, I would be lying if I said I had never experienced feelings of mental anxiety in my life. I had one of those perfectionist, type-A personalities in my younger years, but, to be honest, that had mostly fallen apart post-children. Still, I had the usual mom worries, like wondering if I should call the doctor when my kids were feverish and lethargic for one too many days, or if my super smart (but very bored) 2nd grader was behaving at school, or if we'd ever be able to afford a 4-bedroom home in California. I had never had feelings of panic or “physical” anxiety (racing heart, shortness of breath), save for the rare event here and there.

Up until my toxin injections, I was living a pleasant, busy, and mostly uneventful life as a suburban mom. Which is why, when I began to experience severe nervous system disruption in the days and weeks following the injections, I knew something was terribly wrong.

It is hard to adequately describe in words the intense and unrelenting mental dysregulation that I (and many others have) experienced after toxin spread; even months later, it is still distressing for me to relive those early weeks. Please know that it may prove impossible to convey the all-consuming psychological torment that my brain and body endured during this period, but I will do my best.

The "body anxiety" symptoms began the day of my oldest son's 7th birthday party, which was 4 days after injections. Mid-morning on July 13th, my body began experiencing heart palpitations and a feeling of extreme alertness, as if someone was continually cutting me off on the freeway. At first, I thought I had simply drank too much coffee, even though I'd had my usual half cup.

As the day wore on, it became increasingly difficult to concentrate on even the smallest things, including simple conversations with my husband and mom friends at the party. My body was completely incapable of sitting still and relaxing. *Danger! Danger!* My body was yelling at me.

"What is it, body?" I yelled back internally, "Calm down, we're at your child's birthday party and there is absolutely nothing to be worried about."

And yet, my body persisted. Racing heartbeat. Difficulty focusing. Inability to sit still. Jaw clenching. I felt like I was on a bad drug trip that wouldn't end.

At some point during the party, I pulled my sister aside.

"I have had the weirdest feelings since getting the injections", I told her. "First I felt like I had Covid, I was dizzy and had brain fog and head pressure, then I got bloodshot eyes, and now...I can't even describe it, but it's like my body won't settle down, no matter what I do. It feels like I'm being continuously startled and can't calm myself."

"That's so weird," she replied. "I didn't feel any of that when I got Botox."

The body anxiety rushes began coming and going every few days. Around two weeks post-injections, a new physical symptom began appearing alongside them: neck muscle fatigue. I was driving home from work early one day, feeling tired from having anxiety rushes all morning, when all of a sudden my head became extremely heavy and began to tilt. I had to prop up my elbow on the steering wheel and use my hand to physically hold my head up so that I could see the road for the remainder of the drive. My neck muscles felt extremely weak and tired, as if I had just done a thousand "CTAR"s (nerdy SLP reference: “chin tucks against resistance” are a swallowing exercise where we have patients push their chin down towards their neck using a resistance ball to strengthen their muscles for swallowing).

The whole time I was experiencing these new and strange (and distracting) symptoms, we were planning an upcoming week-long trip to Chicago to visit my husband's family. I kept telling myself that surely I was just nervous about traveling with three young children. I desperately tried to speak louder than the intuitive whisper in my head, "nothing has felt right since July 9th." My intuition knew what was happening the entire time, but I tried to simply ignore it, hoping all of my symptoms would fade in time.

Looking back on this time period, I am reminded of the mental battle I went through when I lost my third baby at 30 weeks pregnant in 2022. I knew the exact time she had passed away because of her sudden lack of movement, but my rational brain kept trying to override my intuition. "Miscarriages don't happen to young, healthy moms, and they certainly don't happen at 30 weeks along." I repeated these thoughts loudly enough in my head in an attempt to block out my whispering intuition: "She's dead." It is amazing how our brains will desperately cling to falsehoods even in the face of loud and clear contrary evidence.

The Chicago trip took place from August 6th through the 13th, a full month after my injections, and during that trip I continued to experience anxiety rushes, brain fog, dizziness, and neck muscle fatigue that would come and go. I, again, would hurriedly put these symptoms out of my mind once they would pass.

On August 13th, we boarded a 4-hour flight from Chicago back home. I had been having body anxiety symptoms since that morning (heart palpitations, "on edge" feelings) and chalked it up to flight anxiety- despite never having felt these symptoms before any previous flight. Once we were on the plane, I put on a movie and tried to work my way through the anxiety with deep breaths and relaxing visualization.

About an hour into the flight, I went to swallow my saliva absentmindedly, and suddenly and without warning my pharyngeal muscles seized up: I was unable to trigger a swallow. I tried to swallow again multiple times, and was finally able to on the fourth try. Alarm bells began sounding in my head.

I realized my mouth was incredibly dry. I reached for my water bottle in the hopes that it would alleviate my symptoms, but it was empty. An announcement came over the speakers and asked that we remain in our seats due to turbulence. I again attempted to trigger a swallow, only to find that my muscles seized up yet again; there seemed to be some kind of glitch happening in my system. I looked over at my husband with panic in my eyes.

"Matt, I need water! My swallow is freezing," I said.

He was holding our squirmy 11-month-old baby and attempting to put on movies for our other two kids. He did not have the time or patience to deal with my request.

"I need water, for some reason my muscles are freezing up," I began to plead.

He looked at me with bewilderment.

"You're fine, Megan, just try to breathe."

We both thought that for some reason my newfound “plane anxiety” had become so extreme that it was causing my muscles to freeze (nevermind that I'd been on more than 50 flights in my life up until then and had never experienced anything like this). I again got a rush of extreme fatigue in my neck muscle area and felt my head becoming incredibly heavy. I laid it down on the tray table and did my best to shut the world out and breathe.

The remaining hours of the plane ride were some of the most terrifying ones I've ever lived through. I continued to try to swallow, and, while my muscles would eventually trigger, they were freezing up every 4-5 attempts. My heart was pounding and my brain was screaming at me: "Something isn't right!! Help!"

By the end of the flight, my saliva seemed to resume its normal production, and I was able to swallow effectively and freely. *Wow*, I thought, *what an odd anxiety symptom!*

After landing, we drove home and I again put the incident out of my mind, telling myself it was simply "anxiety", and now that I was home, surely these weird symptoms would all come to an abrupt end.

Once we returned home, however, the severe nervous system disruption really set in. I had been through my share of difficult life experiences up until that point, having lost a best friend and a baby, but all of that proved to be mere child's play compared to what I was about to live through.

Over the course of three weeks at the end of August and early into September, I experienced daily, terrifying, all-consuming panic and anxiety rushes. Every day I'd wake up to a living nightmare, with no sense of how or when it would end. The attacks would come out of nowhere, whether I was sitting at home calmly and happily playing with my baby, or driving on the freeway to go see a patient. There were no identifiable triggers, and the panic would last anywhere from 20 minutes to more than 6 hours. They were not typical panic attacks like the ones defined in psychology textbooks. The best way I can describe them is feelings of intense nervous system misfiring, pervasive thoughts of impending doom, and physical symptoms like complete paralysis of my swallowing muscles for seconds at a time, heart palpitations, lightheadedness, chest pain, numbness in my arms, and difficulty breathing.

THE FACTS: A large portion of people who experience botulinum toxin spread go through a period of intense anxiety and panic, likely due to the toxin settling into and blocking function within the Vagus nerve. In Bai et al.'s study (1) of 86 iatrogenic botulism cases, they found that 41% of patients suffered from anxiety following toxin spread. Additionally, anxiety is listed as a "very common" side effect of botulinum toxin A on Drugs.com (4).

Every single time they happened, my brain was convinced I was dying. I would clutch my throat and yell at my husband, "I can't swallow, I can't swallow! My muscles aren't working properly!"

After the first full week of these frightening episodes, I finally decided I was going to the ER - my symptoms were becoming too disabling and persistent to ignore. August 21st was my first out of six total ER trips, most of which ended with medical personnel giving me puzzled and pitiful looks as they tore open another milligram of Ativan for me and assured me I was definitely just "anxious" and not at all experiencing botulinum toxin effects.

On the first trip, I arrived at the ER with the following complaint: ever since receiving BoNT injections on July 9th, I had been experiencing very odd neurological symptoms, including head heaviness, neck muscle fatigue and weakness, random "freezing" of my swallowing muscles, severe brain fog, and rushes of anxiety that were completely unprovoked and unlike anything I'd ever been through. Could any of these symptoms be related to the injections?, I wanted to know.

The Physician's Assistant (PA) who saw me did a partial cranial nerve exam - I looked great! No (visible) muscle weakness or paralysis. Surely it wasn't the injections that were causing my symptoms; did I want a CT scan to rule out brain cancer?

"No thanks," I politely declined, due to the large amount of radiation involved and my (correct) sense that a CT would provide zero insights into what was happening in my body.

“Is there any way you can test my blood for the presence of botulinum toxin?”, I asked before leaving.

“No, sorry, we don’t do that here.” (Or, virtually anywhere, I would later learn. Stool and blood tests for botulinum toxin have to be specially requested by state health departments from the CDC headquarters in Atlanta, GA. These tests have to be done in the first 24-72 hours post-exposure, as the toxin, once in the bloodstream, tends to get taken up into the nerves fairly quickly, and does not show up in blood tests after about 3 days. "Antitoxin", the antidote to botulism, is reserved for severe cases where descending paralysis is actively occurring, and when needed is airlifted to hospitals from the CDC.)

All of my basic blood tests and vital signs looked normal, and the discharge nurse told me to stop worrying and follow up with my primary care doctor the next day.

I think back to that initial visit to the ER often.

If the PA that evening had taken 30 seconds to look up, "Botulinum toxin side effects", he would have found nearly every symptom I was experiencing. The knowledge that my symptoms were signs of botulinum toxin poisoning would have cleared up a lot of questions and sent me on a completely different path; one that would not have involved multiple, costly ER visits.

(Interesting sidenote: I kept plugging my symptoms into AI medical symptom checkers and "botulism" would reliably show up on every platform I used. Sadly, I think the robots are already thinking more critically than most of us humans.)

The ensuing weeks leading up to my birthday (September 14th) were a complete blur of panic, crushing fatigue, and insomnia. Life as I knew it was imploding, fast. I was now regularly leaving work early to go home after debilitating anxiety rushes that would leave me bedbound and incapable of caring for my kids. My neck muscles felt fatigued all the time, and my swallowing muscles were still “tripping up” intermittently. I was living in a completely unfamiliar and unpredictable brain and body, and woke up each morning having no idea which new and disturbing sensations the day would bring. My husband had taken over almost all of the household, cooking, and childcare duties single handedly. I was finding myself back in the ER every couple of days with feelings of sheer terror and complaints of severe dry mouth and pharyngeal muscle "freezing". Most of those visits can be summarized by this quote from the exasperated attending PA the second time I was there:

"Open your mouth. See? There's nothing in your throat. Now learn how to handle your stress before it handles you."

Some providers were more sympathetic. They tried giving me various drugs to help with the panic and severe insomnia that had set in. One doctor prescribed Hydroxyzine for my panic attacks, a drug I later learned is a big no-no for botulism poisoning. Hydroxyzine, like Benadryl and Zyrtec, is an anticholinergic drug, a class of drugs that further exacerbate botulism symptoms. I remember taking it once and as it set in, feeling like surely, I was about to die. My breathing became incredibly "lazy" (like I was trying to pump air into a tire that had a hole in it), and for some reason my brain kept telling me to concentrate on each breath or else they would end. It did nothing for my panicky feelings except make them ten times worse. I threw the rest of the bottle away.

I did end up taking small amounts of Ativan a handful of times in those early days. I was worried about taking such a potent drug initially (my medicine cabinet at home was full of organic tinctures and beef organ pills), but it proved to be the only thing that could reliably knock me out so that I could sleep more than three hours in a row. I guess pharmaceuticals aren't all terrible, though one could reasonably argue I would not have been in this situation had it not been for another pharmaceutical. Sigh.

> ***THE FACTS: In Bai et al.'s study (1), they found that 38% of IB patients suffered from insomnia. "Trouble sleeping" is also listed on Drugs.com (4) in the side effect profile for botulinum toxin A.***

I soon had a completely dried out mouth and white, cracked tongue. My saliva production had reduced to about 10% of its norm, and I was finding it increasingly difficult to swallow solid foods. I would look longingly at a pretzel or Chipotle chip, and my brain would say, "Nope. Not enough lube. Not going down today."

Every other day, I would get brave enough to try to eat something like ground beef or rice, only to have feelings of globus (feeling like something is "stuck") in my esophagus, and dozens of throat clears, for hours afterward. My body stopped wanting to eat solid foods because of the immense discomfort that would ensue. I had also completely lost my appetite, and I quickly shed 20 pounds.

On September 4th, I had an in-person appointment with my primary care physician. I mustered as much energy as I could (by this time, I was so physically fatigued and brain foggy that I had gone on disability leave from work and was couchbound for most of the day) and explained everything I'd been through in detail.

"You're definitely experiencing some kind of reaction to the toxin," she replied. "I’ve never even met you before today, and you have no medical conditions or abnormal labs. Is it possible the toxin hit a cranial nerve?", she wondered.

This doctor was the first person I had encountered who seemed to be taking my symptoms seriously, and I felt an instant surge of hope. She got out a tongue depressor to test my gag reflex.

"Um, I just touched your posterior pharyngeal wall, you didn't feel that?"

"Nope," I replied. My gag reflex was nonexistent (no sexual jokes, please!).

Okay, she agreed, something was definitely wrong. She wanted me to go in for a Modified Barium Swallow Study (MBSS) to determine if I was experiencing any impaired pharyngeal or esophageal muscle functioning. She ordered extensive lab work for me (all normal!), took note of all of the symptoms I had experienced up until that point, and documented the following in my medical record: adverse effect following botulinum toxin, muscle weakness, fatigue, dry mouth, difficulty swallowing, anxiety attacks, insomnia, hair loss. (My hair had been rapidly shedding with each shower since a few days after injections, something I had up until this point written off as delayed postpartum hair loss, despite never having noticeably lost hair through four postpartums.)

She was the first (and sadly, the only) medical professional who not only listened to me, but also acknowledged my suffering and agreed that I was, indeed, experiencing adverse effects of botulinum toxin. To this day, she is the only doctor I will ever again trust with my health. All that being said, there was nothing she could do to help me, as there is no cure or treatment for toxin spread except time.

The week after our appointment, I was back in the ER again with worsening globus sensations and a burning throat. I calmly and coherently explained all my swallowing symptoms, and the fact that I had lost significant weight, to the attending PA. I desperately needed someone to look at my swallow. They told me they could do a chest x-ray and a CT scan, but that scopes and swallow exams were reserved for emergency purposes.

"I've lost 20 pounds in a month and can no longer eat solid foods, and am lucky if I get 3 hours of sleep at night. I cannot work or care for my children and am couchbound most days. At what point am I considered an emergency?" Not yet, apparently.

I went back to the waiting room. A radiology technician called me back for my chest x-ray (that I knew would be clear).

"What I really need is an MBSS," I told the tech.

"Oh? Why don't you just call Natalie, the SLP at the hospital? She might have time to fit you in."

Genius! How had I not thought of that myself? I knew Natalie’s name from all the paperwork I would receive from the hospital when I got new patients on my caseload. I immediately got in touch with her to see if she might be able to fit me in for a swallow test.

She did, in fact, have time to see me, and told me she would come down to the ER as soon as she could. What an absolute angel, I thought, there are decent humans left in this world! Hours later, when she called me back, I was so relieved and happy to see her, I almost cried. Finally, someone from my own tribe!

I sat down and told her everything; I started with the botulinum toxin injections, and how I had not felt the same since. I reported all of the weird swallowing sensations and dry mouth that had evolved in the previous weeks, and the fact that my doctor was concerned about potential cranial nerve damage.

"You do have a really dry mouth, and it seems like you're very anxious," she observed.

"Yes, I've had these nonstop waves of anxiety since about a week after the injections. They are exhausting and I have no idea why they’re happening. I keep telling my body there's nothing to be anxious about. My mouth is so dry, and it feels like I have to swallow everything really hard. I also have no gag reflex whatsoever, want to see?"

"Oh no, that's fine," she replied, "I don't do cranial nerve exams."

She proceeded to let me know that she had recently started taking Lexapro, and that it had been a "life-saver" for her. After all, us SLPs are all an anxious bunch, she laughed.

She brought me back to the radiology suite, and I was presented with food and liquid textures that were pre-mixed with barium solution so that the entire swallowing process could be visible on x-ray. We started the test and the thin liquids went down fine. Although my swallow initiation was delayed (which can happen with severe dry mouth and slowed tongue movement), there was no liquid entering my lungs (called “aspiration”), hallelujah!

It was time to take a bite of pudding.

"I'm really nervous to eat this, I may have to wash it down with liquid...solids have not been going down well for me," I warned her.

I took the bite and did my best to swallow, although it felt strained and my chin kept jerking down as I attempted to do multiple swallows.

The x-ray technician continued to keep the x-ray machine on, and I heard a murmur from him:

"Stasis?"

"Yeah," replied Natalie.

I told them the pudding felt stuck and asked for a sip of water to get it down.

"Okay, let's try those all again in AP view," Natalie said.

"AP", or anterior-posterior, view is where the patient faces the x-ray machine straight on (rather than having their side profile face the machine), so that the entire esophageal peristaltic process (when the muscles of the esophagus contract in a wave-like manner to push our food down) can be viewed, from mouth to stomach.

After I finished swallowing everything (except for the cracker, that was an absolute no-go), she called me over so that we could watch the video together. In AP view, we could clearly see that both the honey thick liquid and pudding spoonful appeared to be moving at a snail's pace once they entered my esophagus.

In my pudding video, a full 35 seconds passed with the pudding lingering, seemingly frozen, in my esophagus before I finally took a swig of water that washed it down fully into the stomach. Typically, this process takes 4-8 seconds. What the hell is going on with my esophagus? I wanted to know.

"Oh, yeah, you have esophageal stasis. Totally normal. You've probably had it your whole life and are just now feeling it because you've been so anxious. Get some high protein smoothies. Look, Megan, I know it's hard, but all of us SLPs are so anxious. We should honestly all be on SSRIs. Why don't you consider them? I'm like a whole new person since I started Lexapro."

I'm so happy for you, but what the hell is going on with my esophagus?!, I wondered.

On the one hand, I was relieved to see that I was not aspirating food or liquid. On the other hand, I could clearly see that my esophageal muscle contractions were not working normally. I was presenting to the hospital with new and recent onsets of absent gag reflex, dry mouth, worsening globus sensations, neck muscle fatigue, and now, visible esophageal stasis, and was being told by an SLP to consider taking an antidepressant? What was I missing?

I nodded along, smiled and thanked her, and went home dumbfounded. Why was no one believing me and addressing my actual symptoms? I was a highly educated medical professional with no prior history of any medical conditions, and was begging for help with new and worsening symptoms. Almost everyone (including a fellow SLP!) I had encountered thus far seemed to be insinuating that, at the age of 35, suddenly and without warning, I woke up one day and thought it would be super fun to fake a bunch of cognitive and physical symptoms, go on disability leave from a job I love, and spend my days rushing around to various doctors and ERs seeking treatment. And lose half of my hair while doing it.

Surely, according to them, I was simply imagining a whole slew of sensations that couldn't possibly be real. So...were they all right? Had I gone insane?

Chapter 3 - Iatrogenic Botulism… and Chipotle Chips

No. They were not right.

I would not be gaslit any longer.

I was a grown woman who knew myself intimately. I knew in my bones that I was a psychologically strong, resilient, and sane person. I loved my life, my job, and my family. I had lived more than 35 years without a single symptom even remotely similar to the ones I was now struggling with on a daily basis.

In the years leading up to this moment, I had lost my best friend to cancer and had given birth to a stillborn, and had made it out of both of those losses with a sound mind and strong heart. I wanted nothing more than to be done with these awful, strange symptoms and get back to enjoying time with my family and serving patients at a job I cared about deeply.

I was not going to let strangers in white coats convince me that I had suddenly gone insane, and that they knew more about my mind and body than I did.

I would not be gaslit any longer.

I went home from my swallow test, pulled out my laptop, and did what I should have done six weeks earlier.

Dear Dr. Google: "botulinum toxin side effects".

And that's when the puzzle pieces finally began clicking.

Beginning with the top search results, including standard websites like Drugs.com and WebMD.com, I quickly found that all of my symptoms, from dry mouth and insomnia to impaired digestive peristalsis and anxiety attacks, were all side effects reported in either the clinical trials or post-marketing data for botulinum toxin injections. "Side effect" is actually a misnomer here, as anyone with a basic science education (hard to come by in this country, for sure) and a critically-thinking brain can understand that these are, in fact, *direct* effects of botulinum toxin spread. They are the result of the toxin spreading from the injected muscle site and doing exactly what it was created to do: blocking acetylcholine transmission at nerve synapses.

Bear with me as I get a bit science-y so that you can have a basic understanding of what botulinum toxin does in the body. I promise to make it simple and relatively painless (unlike botulism).

Botulinum toxin, derived from the bacteria *clostridium botulinum*, once injected into a muscle, begins to find and attach to nerve synapses (where two nerves meet). Once there, it blocks the release of acetylcholine, a neurotransmitter that carries chemical messages from nerves to muscles or other nerves. The toxin's incredible ability to bind to these synapses (or “junctions”) and destroy them is why our muscles experience temporary paralysis. The reason muscle movement returns 3-6 months after injections is because our bodies are truly incredible, and actually begin to sprout new (albeit likely not as strong) nerve synapses around the permanently damaged ones.

A bolded Black Box Warning (the FDA's strongest warning for pharmaceutical products) sits at the top of the package inserts for all botulinum toxin products (including Botox, Xeomin, Dysport, Jeaveau, and Daxxify). Xeomin's states the following:

"WARNING: DISTANT SPREAD OF TOXIN EFFECT. The effects of XEOMIN and all botulinum toxin products may spread from the area of injection to produce symptoms consistent with botulinum toxin effects. These symptoms have been reported hours to weeks after injection. Swallowing and breathing difficulties can be life threatening and there have been reports of death. The risk of symptoms is probably greatest in children treated for spasticity but symptoms can also occur in adults, particularly in those patients who have underlying conditions that would predispose them to these symptoms."

Toxin spread beyond the intended muscles can happen through one of three ways: through the bloodstream (by accidental injection into a blood vessel, as was likely the case for me due to my immediate neurological symptoms), diffusion of the toxin through adjacent muscle tissue, or a process called "retrograde axonal transport" where the toxin spreads backwards along nerves from the injection site (2). In Xeomin's own placebo-controlled trial data (5), toxin spread happened anywhere from 1% to more than 10% of the time, depending on the injection site. Dry mouth, eyelid ptosis, dysphagia, blurry vision, muscle weakness, fatigue, UTIs, and dysphonia (hoarse voice) are all direct effects of toxin spread.

The research on “iatrogenic botulism” (botulism that occurs following injected BoNT, as opposed to foodborne and wound botulism) cases, especially long-term outcomes, is shockingly thin. Bai et al (1) divided IB into three severity categories: mild, moderate, and severe. I seemed to fit in the “mild botulism” category, because I wasn’t suffering from any muscle weakness or paralysis that was severe enough to warrant a feeding tube, ventilator, or wheelchair. Mild botulism cases included symptoms like dizziness, nausea, anxiety, fatigue, blurred vision, dry mouth, and muscle weakness. On paper these symptoms look pretty "mild", but I can assure you that nothing I had experienced up until this point was anything of the sort.

As I continued digging into medical literature for answers, it became increasingly clear to me that many of my symptoms were likely stemming from the toxin settling at various points along my vagus nerve, and even traveling to my central nervous system (CNS).

The vagus nerve, or Cranial Nerve X, is the longest and farthest reaching cranial nerve in the body, originating in the brainstem and ending in the intestines. It innervates the muscles involved in a wide variety of bodily functions, including respiration, digestion, speech, and swallowing, to name only a few. It makes up the majority of the parasympathetic nervous system, also known as the "rest and digest" part of our nervous system, and it helps modulate our sleep cycles, digestive peristalsis, saliva production, and feelings of relaxation. Disruption to the vagus nerve can lead to a plethora of issues that mimic a state of "fight or flight" (anxiety, racing heart, dry mouth, constipation, insomnia, etc.).

The only articles I could find that addressed the extensive nervous system effects that followed potential vagus nerve and/or CNS disruption from botulinum toxin came from a researcher named Dr. Anna Hristova. She is the only neurologist in America who has published case studies following IB patients for an extended period of time (4+ years). She coined the term “Impaired Neuronal Communication Syndrome” (or “INCS”) to define the severe and wide-reaching bodily disruptions she was witnessing in patients who had received BoNT for both cosmetic and therapeutic (migraines, muscle spasms) reasons.

In her article about the topic, she writes, that, in addition to peripheral nerve dysfunction,

“Research has established that botulinum can block many mediators in CNS" and "The most common (CNS) symptoms (of INCS) are impaired concentration, word finding difficulties, impairment of memory, significant head pressure, phono- and photophobia and inability to multitask...Most of all, there is a mental fatigue which often leaves the patients debilitated and with the ability to only do a few tasks before exhaustion sets in.” (3)

Hm. I had been calling my current mental state "brain mush", but this sounded much more scientific. She goes on:

"Psychiatric symptoms are very common and debilitating, such as severe anxiety, panic attacks, feeling desperate...and fixated on the symptoms." and "(the) most common and disabling (autonomic nervous system symptoms) are: shortness of breath, arrhythmia, heart racing, palpitations, chest pain, dizziness, dry mouth, dry eyes, and stuffy ears..." (3)

Her study is lengthy, but well worth reading, as it highlights the wide range of debilitating, and, quite frankly, terrifying mental and physical symptoms many IB patients experience. When I first came across it, I felt like someone was finally giving words to the hell I had been living through for the past two months. There was even an acronym for it!

If my peripheral (including autonomic and parasympathetic) and central nervous systems had indeed both been disrupted by toxin spread, it would explain all of my symptoms: brain fog, head pressure, anxiety rushes, a complete lack of appetite and 20 pound weight loss, absent gag reflex, lack of saliva, impaired esophageal/intestinal peristalsis (and subsequent constipation), insomnia, and a new fun one that had recently settled in, ear congestion.

The ear congestion (or, "stuffy ears", as Dr. Hristova called it) came on suddenly on September 16th (a full two months post-injection - by now I was keeping a meticulous log of symptoms). I began to feel like I was on a plane that was taking off, all. the. time. I'd "unpop" my ears, only to have them "fill up" 5-10 seconds later. This process began repeating itself. All day. Every day.

"Don't go mad, Megan," I told myself during an internal pep talk. "You have to stay strong so you can figure out what to do next."

In my online search for botulinum toxin side effects, I came across a support group titled "Botox (Dysport) Side Effects Support". I joined eagerly but was quickly overwhelmed. Oh, my God.

Story after story with all-too-familiar symptoms, unfolding just like mine had. Tens of thousands of women and men that had been through the same medical gaslighting I had endured. Some had experienced adverse effects on their first injections, others had been receiving BoNT injections for more than 10 years before ever having a single reaction. Some had had as little as 5 units once, while others regularly received over 100 units multiple times per year.

I felt immediately vindicated, but was also unnerved by what I was reading. Some of these members were 12, 24, even 36 months or more out from injections, and still seeking advice on how to deal with their lingering symptoms.

I began voraciously combing through the support group posts. I learned that for most people, healing was nonlinear, and required large amounts of time, patience, hope, sleep, and electrolytes. Symptoms seemed to come and go over the course of years for the vast majority of members, but many made significant improvements in the first 12-18 months post-injections. (Turns out, no one has a great explanation for how the body processes botulinum toxin once it has entered the bloodstream, and it is likely that the toxin can continue to circulate and cause damage for at least a year post-injection.)

The support group was full of helpful information about how to deal with the varied symptoms that can occur, depending on which nerves the toxin settles into, and they even had a list of strict “Botulism Don’ts” (e.g.: anticholinergic drugs, SSRIs, fluoroquinolone antibiotics, epinephrine, massage, acupuncture, and chiropractic care, to name just a few), due to the potential these drugs and procedures have to exacerbate symptoms or further toxin spread.

Much of the information had been compiled from various (albeit limited) research and the combined anecdotes and wisdom of tens of thousands of members over the course of more than eight years. The women who ran the group had either suffered from IB themselves, or had close family members who had. I found immense comfort reading through the healing stories in the group, and clung to those testimonials as gospel, as I was desperate for hope and relief. The support group was truly a lifeline during the darkest period of my life, and I know many other people who feel the same way.

As reality was setting in, I decided I unfortunately had to reach back out to Dr. Perfect Skin again. I knew she would likely find a way to dismiss my symptoms, but I wanted to get the lot number for the toxin batch I had received, and also receive a refund for my remaining membership funds at her practice that I definitely would not be using. Additionally, I felt strongly that she needed to, at the very least, report my side effects to FAERS, the FDA's Adverse Events Reporting System.

I initially contacted her office via email, and I also sent them a private message on Facebook.

Days went by without a response.

I'm old school, so the following week I hired a babysitter to watch my kids and showed up at her office in person.

Surprise, your favorite patient is back!

After her staff hid me away in an exam room for 50 minutes, I finally came out (severely thirsty from my dry mouth) and ran into her standing in the hallway.

"How are you?", Dr. Perfect Skin asked while hugging me. "I got your emails, Megan. There's...a lot there..."

Tears and words began pouring out of me. I was incredibly emotional as I recounted how I had been struggling to make it through each day for the past few months. I told her that I was unable to take care of my children most days due to extreme fatigue that left me couchbound for hours. I told her about how I had been on disability leave from my job for the past few weeks, and that I was experiencing brain fog, insomnia, dry mouth and constant globus sensation in my esophagus. I emphasized that I had lost 20 pounds and about 40% of my hair. I handed her a paper copy of all of my symptoms, with the accompanying onset dates.

"Wow," she said flatly, "That's so rare."

That's it? I thought. To be fair, she had a perpetually flat affect, and her face was so frozen from all the Botox that it was always hard to know if she was experiencing real human emotions or not.

Indeed, rare but very real. Would she please report my side effects to the FDA? It was the best way for the FDA to track adverse effects from drugs, and thus provide accurate information to the public regarding the potential risks of these products.

"I'll be sure to let my Xeomin rep know, thanks."

I'm sorry, what? Your "Xeomin rep"? As if they care?

"No, I need you to report my side effects to the FDA," I insisted with teary eyes.

She again let me know that she would email her Xeomin rep, and that there was nothing she could do for me. She was also very busy injecting others with Botox, so... best wishes on your recovery, Megan! Off you go now!

Deep breaths, Megan. Deep breaths. I still don't know how that woman sleeps at night.

I want one of the biggest takeaways from my book to be this: there is nothing, and I mean absolutely *nothing*, that any doctor can or will do for you if your botulinum toxin injections go wrong. It can (and does) happen (much more frequently than you've been told) with any injector, any brand, at any time, with any amount. If you don’t believe little old me, here is Dr. Hristova again,

“Our data demonstrate that a generalized spread of the toxin can occur even after years of uneventful toxin therapy. Patient #7 had 30 successful treatments over a decade before the adverse events occurred. Prior uneventful injections cannot be a predictor for toxin safety, because in our experience, generalized spread can occur at any time and with any injection.” (3)

The doctor or nurse who injects you, regardless of how chummy you are with them, will completely dismiss all of your symptoms as “impossible” and “in your head” (despite the fact that they are all listed in black and white on the manufacturer’s website and in post-marketing data reporting). They will take no responsibility, and they will be unable to help you. They will not rush-order anti-toxin for you. They will not report your symptoms to the FDA. They will sweep you under a rug, and there you will stay. They will continue to go about their life and line their pocket books by injecting people with poison without giving them proper informed consent.

You will suffer in silence, unheard and unseen, for many, many months.

One more time for the folks in the back: There is no treatment. There is no cure. There is no accountability. The end.

I hate to sound so jaded about all of this, it goes against every bone in my innately optimistic body, but I have sadly heard my exact same story (with different names and faces) thousands of times.

The reality of these injections and the nightmares endured by those who have suffered from their adverse effects can get extremely dark very quickly. If I had not lived through this myself, and spoken to hundreds of people who suffered for *years*, I might not have believed it was true. After all, you won't find any of our stories in a quick Google search.

Some of you may be thinking, I'm so sorry this happened to you Megan, but it *is* incredibly rare. And to that I say, *Is it, though?* How do we know that?

Per the manufacturers' *own* data and admission (and I've read through the clinical studies for each brand), the risk of toxin spread is at least 1 to more than 10% *with every injection*, depending on the location.

These percentages do not seem that small to me, especially when millions of injections happen every year. I know if I had been given true informed consent, and had seen those numbers prior to my appointment, I would have promptly cancelled. That is far too high of a risk-benefit ratio for me; I have a family to raise, a career to manage, and a life to live beyond my couch.

In the months since I have fallen ill, I have met three people just in my immediate social circle who had all suffered from my same symptoms post-Botox injections for either cosmetic or migraine purposes. One was a

30-something mom whose potassium was so low at one point she almost went into cardiac arrest (botulinum toxin, once in the bloodstream, acts as an antagonist to potassium).

I think perhaps what is really going on is that direct effects from toxin spread are happening regularly, but people are either not talking about their symptoms with others, or are not even correlating their symptoms with the injections, as effects can appear after the 5th, 10th, or 20th injection. Some of them may have symptoms that are more subtle and transient (anxiety attacks, fatigue, insomnia, dry eyes or mouth, heart arrhythmias, blood pressure spikes and dips, dizziness, nausea, headaches, UTIs), depending on how much toxin enters the bloodstream and where it settles.

For the people who go on to develop severe effects and report them to their doctors, validation is hard to come by.

Misdiagnosis, or no diagnosis at all, is extremely common with iatrogenic botulism, as almost all of the symptoms, particularly with mild botulism, are subjective experiences (feeling short of breath, anxiety, nerve pain, dizziness, dry mouth, globus sensation, fatigue, etc), and thus leave many modern doctors confused. (Doctors from decades past, pre-technology, were typically quite good at diagnosing botulism simply by listening to their patients and knowing the warning signs.) Objective tests rarely show any markers of disease, and there are no readily available objective tests for botulism. Diagnosis can only come from believing patients' subjective experiences, asking about prior BoNT injections, and understanding the wide variety of bodily processes that can be affected by BoNT once it has entered the bloodstream. A diagnosis of botulism is essentially a ruling out of other diseases with similar characteristics. It requires doctors to be perceptive and discerning, and to question the narratives that have been drilled into them by companies who have billions of dollars in revenue at stake.

Since most IB cases fly under the radar with no one the wiser, what we're left with is inaccurate post-marketing reporting data (FAERS) that is likely only reflecting a very small percentage of people with the illness. For the cases that do raise attention, pharmaceutical companies likely rush to hide their victims' stories behind NDAs in exchange for large amounts of money. Their bags of money and far-reaching tentacles can ensure our stories are never seen on internet search engines, in national newspapers, or during nightly talk shows. (No citations here, just educated guesses.)

However, this book is not the place to get too conspiratorial (although I'll gladly do that in person with you!), and I want to switch gears back to some of the positive healing progress my body began making in these weeks. Because as emotionally distressing and overwhelming all of this new information was, my body was making slow but steady healing progress.

The anxiety rushes and insomnia had ended abruptly, as quickly as they had come on. My final body anxiety attack occurred on September 17th. I have not had a single one since. I have no idea why or how they ended, but was not about to dwell on the matter. I was just so relieved to have made it through the horror show.

Once they were over, I was better able to focus on nourishing my body and modifying my diet to include the highest amount of nutrients, calories, and protein with the least amount of esophageal discomfort. Thin liquids and “mildly thick” liquids (think protein shake consistency) were going down just fine, and they made up the bulk of my calories during this time. Pureed foods went down okay, as long as the consistency was extremely smooth, and I washed them down with water immediately after swallowing. Anything gritty or lumpy caused remaining residue and produced feelings of uncomfortable globus (and many throat clears) for hours.

I learned a lot about keeping my mouth as hydrated as possible to temporarily relieve the feelings of extreme dryness. I found some effective oral moisturizing products online (my favorite was “XyliMelts” on Amazon), and plain old chewing gum helped with saliva production as well. I chugged electrolytes religiously throughout the day (and spent a fortune doing so).

After almost a decade of working with them, I had become a homebound patient myself. Sure, I could see the life lessons that were unfolding in real time for me, but that didn’t make the situation any less depressing. Most days I felt like a 95-year-old on their deathbed. I had severe dry mouth and cracked lips that no amount of water relieved, inability to eat most solid foods, and was in a constant mental state of brain fog and fatigue, mixed with increasing apathy and hopelessness.

I was missing out on so many activities and life events with my family: soccer games, gymnastic practice, parent-teacher conferences, my own birthday dinner. I had to decline social invitation after invitation to instead lie in bed, frustrated and teary eyed.

It felt like the toxin had hijacked my life and wouldn't let go.

Every day, I wondered if and when my condition would improve. When would I be able to enjoy eating dinner with my family again? When would I be able to socialize with friends again? When would I be able to go back to work and earn a living again?

I dreamed of tough, crunchy, salty foods and what it would feel like to again swallow normally without discomfort. I decided that when my dry mouth and globus cleared up, steak would be the first food I'd have. Or Chipotle chips. It was a toss up.

And then, October 11th happened. I will never forget that day.

We were driving home from my son's soccer game (one of the few I was able to attend that season) when I began feeling unusual, yet familiar, sensations.

“Matt!”, I yelled at my husband. “My saliva just came back! Oh my god, my saliva is back!”

I pulled down the car visor mirror, stuck out my tongue, and witnessed pure pink gloriousness. My saliva was really back. As if it had never even left me for seven weeks. As if my tongue hadn’t been cracked and white for 49 days. MY SALIVA WAS BACK!!!

(Although it would continue to come and go to various degrees from then on, after that day, my saliva never dipped back down below 30-40% of its usual production, which was all I needed to enjoy solid food again.)

I can’t put into words the elation I felt.

It was like I was reborn.

I was suddenly full of energy. Smiling, laughing. Running through the grassy knolls of Austria with arms outstretched. Wanting to eat anything and everything I had been missing out on for the past two months.

The Chipotle chips won.

Chapter 4 - Functional but Foggy, with Really Bad Hair

As my more concerning symptoms (dry mouth, globus) improved with each passing week, other ones that had taken a backseat became more noticeable.

By mid-October, I was back at work (very part-time), and beginning to realize that I was still suffering from moderate brain fog and fatigue that fluctuated by the hour.

I've always considered myself to be a quick learner and sharp mind. My job is cognitively demanding, and I usually love the challenges it comes with, both intellectual and emotional. I was finding, however, that my brain was having a hard time coming back "online". Tasks that had always been easy for me, such as being emotionally present with patients during therapy and problem solving in real time, felt like enormous hurdles that I had to struggle through minute-by-minute.

I was also distracted by my 24/7 ear congestion, which resulted in me adapting all kinds of embarrassing tics to equalize the pressure in my head. Jutting my lower jaw forward seemed to help sometimes, as did short, intense nasal sniffs (that made me look and sound like a cocaine addict). Most of the time, though, I simply had to plug my nose, puff out my cheeks, and blow air out of my ears. Every 60 seconds. Not awkward or annoying at all, especially as I'm trying to actively listen to and educate my patients (while not appearing crazy).

At this point, I was somewhere in the bargaining stage of grief: "Okay fine body, I'll take the dry mouth back if you can make the ear congestion go away!"

My symptoms would come and go, just like all of the members in the IB support group had reported. My body would feel energetic and relatively normal some mornings, only to grow heavy and lethargic as the day continued, as if someone had draped a weighted blanket over my head and limbs. I’d have two great days symptom-wise, and then be met with three subsequent awful days of sinus pressure, dry mouth, nonstop ear pressure, brain fog, and fatigue.

My kids brought home a routine cold from school at some point, and it left me bedridden for four days. I had the energy to walk to and from the toilet a few times a day. That was all.

On the good days, I was functioning well enough, but the vast majority of the time I was merely counting down the hours until I could return to the only true break I got from symptoms - sleep.

By this time, I had cut my hair off into a Tilda Swinton-esque pixie, as I had lost close to 50% of it (a very unfortunate botulinum toxin effect - turns out acetylcholine transmission is needed for hair as well). I figured if it was shorter I’d be less likely to notice the strands that shed every time I showered.

I was not prepared for just how depressing hair loss would feel, especially as I began to see parts of my scalp that I'd never seen before emerging; my hair was a big part of my identity. I had spent the past two years ditching hair dye and growing out my grays, and was totally in love with my "skunk stripe" (strip of solid white hair in the front). I was devastated to witness the globs that were coming out each time I washed it, as well as the dozens of strands I'd wake up to each morning on my pillowcase.

(It needs to be said, because many have questioned my assertions that my hair loss was caused solely by the toxin injections, that yes, my hormones, thyroid, and nutrient blood tests were all normal. No, I had not recently had COVID or the vaccine. My hair began noticeably falling out a mere 4 days post-injections, before I had even begun to experience more serious adverse effects. I lost 50% of it in 4 months' time by my estimates.)

I contemplated wearing a wig, and even tried out extensions, but at the end of the day, I just couldn't muster the energy to care about what I looked like anymore. I was defeated. You won that round, botulism.

I eventually just embraced my thin, fragile, awfully-cut hair the way it was. The 90's were in again, after all, so my greasy pixie wasn't totally out of place. I bought some ribcage-high Levi's to complement my new look. I kept thanking my lucky stars I was married prior to my poisoning, as surely I would have scared off any potential suitors with my recent onslaught of strange and unattractive physical and mental symptoms.

I scoured the IB support group for positive stories about hair regrowth, only to find mostly inconsistent experiences (a very common theme in the IB world). Some members found that their hair thickened back up in the 2-3 years post-injections, but others were more than three years out without seeing any new growth. A handful of women had even lost their eyebrows and eyelashes in the months post-poisoning.

Take a pause from reading and please put yourself in their shoes for a moment.

Imagine losing your eyebrows and eyelashes.

From this stupid little toxin.

Utterly devastating.

I have continued faith that my hair will thicken back up, and I certainly take enough beef organ supplements to ensure it has no excuses to not grow back. But, if I've learned anything about botulism poisoning, it's to be ready for everything, so who knows, I might be bald by the time you're reading this.

I have to say (and am speaking now solely into the universal void), it would have made this whole ordeal *slightly* more emotionally manageable if I hadn't lost half of my hair and dropped at least four points on the attractiveness scale in the process. (Joke's on me there - I went in for a "youthful", "aesthetic" procedure and came out of it looking 10 years older from all of the insomnia and hair loss.)

Alas, hair schmair.

What I really wanted was my brain (and life) back.

Chapter 5 - My New Normal

Weeks passed; I was settling into my new normal.

My pattern of symptoms had become somewhat predictable, in that they were completely unpredictable. Botulism life is truly like a box of chocolates, you never know what you're going to get each day.

Every symptom would come and go in waves, they seemed to be a bit better in the morning and the evening. Everything got significantly worse in the days leading up to my monthly cycle, a phenomenon many of the women in the group lamented over.

But, on the whole, my symptoms were improving, and I had faith I would continue on a "two steps forward - one step back" trajectory as the months passed.

A week before election day in November, my oldest son who was 7 at the time tapped on my shoulder,

"Mama, if I were president, I'd ban Botox...and homework."

See? Smart kid.

The effects this illness had on my relationships with my children were devastating, but each of them had their own unique and sweet way of showing me their unconditional love, and for that I was immensely grateful. Every day I longed to be as physically and emotionally available as possible (and to give my poor exhausted husband a much-needed break). Many days left me with overwhelming sensations and symptoms that prevented me from being totally present with my kids, but on the days where I felt even small amounts of energy and clarity, I relished the feelings of normalcy and the opportunity to do more activities with them.

I had to forgo our usual Thanksgiving festivities of driving down to Pacific Grove to visit extended family, as I was mentally and physically in a very bad place. Every couple of weeks, I would go through periods of sinking into absolute despair, where the reality of the last few months of my life would come crashing down on me all at once and cause an outpouring of emotion and tears.

What was happening to me? Where was my normal brain? Where was my normal body? Where was all my damn HAIR?! In the words of 7-year-old Youtube star David*, Was this real life?*

My dad stayed with me during the holiday, insisting that I watch Tim Allen's sitcom with him (it was either that or Fox News, so I chose the former). I realized I hadn't sat through a sitcom since watching Allen's original show Home Improvement (also with my dad) when I was in elementary school. We had come full circle!

The strength and patience required of people who have a loved one suffering with IB is immense, and not for the faint of heart. To my husband, parents, and children, I want to say: you will never know how much your love, reassurance, and simple presence throughout this unimaginably traumatic experience has meant to me. I cannot wait for the day that I can repay all of you for taking care of me during this time. Thank you.

I was hoping to be able to tell you that I was completely symptom-free by the time I published this book, but, unfortunately, I, like many IB folks, still struggle with waves of symptoms that come and go. I have transient feelings of dry mouth, fatigue, brain "mush", and ear congestion throughout the week. I have random incidences where my brain stem seems to "trip up", and my pharyngeal muscles freeze or my lungs skip a breath. I have unfortunately had to leave work early a handful of times due to intense, uncomfortable symptoms popping up out of nowhere.

I have improved tremendously in my ability to deal with these symptoms in a calm, neutral manner. When I start feeling "toxy" as I call it, I stop what I'm doing, go straight to my couch or bed, and breathe deeply while reminding myself that the sensations will eventually pass, as they always do. I will myself to focus on the incredible progress my body has made, and that it will continue to make. What beautiful, self-healing machines we are blessed with.

I would not be doing my due diligence if I did not stress that even after everything I have been through, and all of the time, energy, sleep, sanity, and hair (!) I have lost to this toxin, my symptoms thus far have paled in comparison to what others have been through.

Cardiac issues, difficulty breathing, feeding tubes, partial and complete paralysis of limbs, 24/7 nerve pain, burning and choking sensations, dizziness, impaired vision, unbearable psychological states of mind, MCAS and histamine intolerances (Google it), and multi-system inflammatory disease, are all just a small sampling of what some people have endured daily for months, even *years*.

Many of us end up disabled for some amount of time with PTSD-like characteristics, having spent endless hours rushing from doctor to doctor for answers, only to be told that our symptoms are simply due to "anxiety" and surely, not that insanely neurotoxic and lethal poison that was injected into our bodies. *Silly, hysterical women.*

We all go through a deep and lengthy grieving process, and eventually come to terms with the fact that modern medicine can't help us. That notion alone can be very isolating and scary to sit with when the symptoms become distressing.

I have attempted to write this story in an entertaining manner, but I can assure you there is nothing remotely funny about what people with IB live through. Careers have been destroyed. Marriages have ended. Families have fallen apart. Lives have been lost to suicide. And that's just the havoc that has been wreaked on those who survive the initial poisoning.

As of December 2024, FAERS reports that over 1,500 people have died from medical complications post-BoNT injections, just in the US (likely a small percentage of actual deaths due to underdiagnosis). We are *risking our lives* (however tiny the risk) to "freeze" wrinkles that no one else notices or cares about. (And yes, I do realize that many people receive BoNT for therapeutic/medical reasons, such as muscle spasms, migraines, tremors, saliva, and sweat. Sadly, the medical IB crowd often suffers the worst of the disease, as they tend to get much higher unit loads per injection, and thus have a higher probability of large amounts of toxin entering the bloodstream. Even though their risk/benefit ratio may be smaller, I still want these people to be fully informed of the potential risks of BoNT injections, and to make their own medical decisions after weighing the pros and cons.)

What I can tell you is that every single IB sufferer in our group, from both cosmetic and therapeutic doses, would give up nearly *anything* to rewind their life back in time and cancel their injection appointment.

I have no idea what my future holds, and whether or not I will go on to develop a worsening of symptoms, new medical conditions, or have "relapses", like Dr. Hristova and many group members have reported. I try not to linger on the fact that in four years, nearly 80% of the patients in her study had not fully recovered to their pre-injection norm. Beyond her work, there is zero research on the long-term outcomes of IB. We are the guinea pigs.

The good news is that the majority of sufferers do seem to improve month-by-month and year-by-year, at least to their “new norm”, which may look different than life pre-injections. It usually means being mentally and emotionally prepared for symptom relapses, having to significantly modify our lifestyles (e.g.: avoiding certain social activities, jobs, exercises, foods, medications, and medical procedures), and never taking feelings of brain and body homeostasis for granted.

I am only one person, and my healing journey is not yet complete, but I hope that by sharing the first few months of my story with the world I have helped others with this illness feel a little more seen and heard. **Together, our stories can and do make a difference in the crusade to save others from our fate.**

I know I personally will never stop talking about the harms of these injections (sorry, Matt!). If hearing my story convinces just one more person to avoid or ditch the "tox", it will help make my suffering feel a bit more purposeful.

And for those of you who may still be considering Botox for cosmetic reasons, might I suggest that you instead...

...wear a hat?
...put on sunscreen?
...consider microneedling?
...stop staring in the mirror and get over it? (You look fine, and the people who truly love you are completely uninterested in your wrinkles.)
...learn a language?

…study Stoic philosophy?
…plant a flower garden?
…open shelled walnuts with a metal lever nutcracker? (very satisfying!)

Please, I beg of you: **Do literally ANYTHING except inject the most lethal poison on planet Earth near your brain and bloodstream.**

The supposed "benefits" are never worth the very real, very destructive risks, despite how hard the pharmaceutical industry has worked to convince us otherwise.

Your body and wallet will thank me later.

10 Life Lessons Learned in 5 Months

1. Health is sacred. Never take it for granted.
2. Don’t let anyone inject you with poison.
3. Nobody cares about your wrinkles.
4. Our medical system is broken. Not many critical thinkers left. The pharmaceutical industry has tentacles everywhere, and does their best to bury unfavorable data.
5. Believe and validate your patients’ subjective experiences, even if you can’t figure out the potential cause.
6. Short hair isn’t totally awful.
7. Pureed meat is totally awful.
8. Reject the youth-obsessed culture that insists beauty can be bought.
9. Play piano. Sing. Heal. Repeat.
10. Go ahead, smile with your eyes.

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And to **Dr. Perfect Skin**, the injecting doctor who kicked off this entire saga. I'm not going to lie. I spent many months being angry at you. Due to a simple mistake you likely made, life as I knew it was completely decimated. I was struggling to make it through every single day for many months; you continued to go about living your luxurious life, without any empathy for or acknowledgement of my suffering. I want you to know that I am no longer angry, and that, by (accidentally) injecting me in the bloodstream with botulinum toxin, you actually gave me one of the greatest gifts I will likely receive in my lifetime. The gift of knowing what true beauty is, and with that, a resolute rejection of the superficial culture that pervades many of our lives as women in this social-media age. You have saved me a ton of money I likely would have wasted on cosmetic treatments, chasing a fantasy of physical perfection that will never exist.

I hope that you, too, wake up to the truth that you are perfect just the way you are, and that you always have been. No poison necessary.