

# Emrys

JOURNAL

VOLUME 26

SPRING 2009



## My Sister and Extreme Health

Stephanie R. deLusé

I lean on my cluttered desk, ignoring stacks of lists and papers, and stare at the computer screen. I'm still deciding, after weeks of largely internal debate, whether to book a flight or not; whether to accept my sister's invitation to meet her in California for the Extreme Health Conference. It is two weeks away. I've highlighted the flight but wonder if I should hit "submit."

Extreme Health . . . . Patty is clearly an example of it. Maybe she's hoping this conference will provide her another temporary miracle to balance the scales that have been so heavily weighted to the negative and get her through life a little further. I think of her health-related journey through life. . . .

My mind goes back to a few years before, when she came to visit me in Phoenix from her home in North Carolina. No small feat for her, I'm grateful she made the trip. She sits without her shirt at my dining room table, as casual as can be, displaying the eight-inch scars reaching from each of her armpits down like chevrons to the lower part of her sternum. Red and rumpled, they still look sore. She shows me where they had to sew flaps of skin, one on each side, like flopped dog's ears, in order to close her up. They told her the scars and the flaps would "resolve" in time, and if they didn't she could have the flaps clipped or something.

*I remember flying back to North Carolina to go with her to meet the breast cancer surgeon. I didn't like him. What can I say? I'm not sure I'll ever like someone who is going to cut up my loved one. But he came highly recommended, so I don't speak my mind—it's not clear how offering my opinion would help. She trusts her doctors. That's important.*

*More important than me planting seeds of doubt when I have no real reason other than "I just don't like him."*

I try not to stare, but I'm curious. I eventually ask to take a good look. I wonder why the flap would matter when the scars are clearly the focal point. . . how could that small detail be about beauty? Maybe it's about comfort? But wait, she had been worried about asymmetry in the event they only took one breast. This reminds me there are different ways of seeing beauty. I quit my ponderings. I don't know the importance of these details and really don't need to right now. I need to act naturally until it IS natural for me to look at her without feeling odd that she is sitting here shirtless at my dining room table. It would be offensive and selfish to say, "Hey, can you put on a shirt?" just to make myself more comfortable, to not have to share in her suffering or remember how many other parts of people, or entire lives, have been lost to cancer in my family by the reminder of her scars.

"Can I make you some tea?" I ask, swallowing my discomfort, as we plan our day.

I think about her self-confidence at sitting here bare-chested at my table as if she'd done it all her life, as many men have done their whole lives. I remember that I contributed to this confidence when we discussed the necessity of having her breasts removed for cancer at the age of 40. After so much talk of all the serious stuff, I tried to lighten it up.

"Well, look at it this way, now you can go to the beach without a shirt. We've often thought if guys can do it, why can't we? I mean, they do it in France, right? So now you can make a statement or test some limits, if you are willing. You can find out if it is women's breasts that make for 'indecent exposure' or just bare-chested women. . . I mean, you won't have breasts, so it begs the question of how would your chest be different than a man's?"

*You may be appalled that I would say this to my sister . . . you may fear it would be too offensive to a woman to be reminded, within days of losing her breasts, that her chest will look like a man's. But you'd have to know my sister to know that she can handle this.*

*Her body is covered with so many other scars, from so many other injuries and surgeries. We talk about the tapestry of her scars not as ugly marks but as beauty marks that show her courage, how she's overcome what has killed others, how she's special to have so many when most have few or none, how some cultures scar themselves intentionally for symbolic and spiritual reasons, so let's look for those reasons in her choices, her scars. This all resonates with her, so my comment about having a man's chest is met with a certain realistic perspective.*

"Huh, I suppose you're right." My sister has a rebellious streak, so this idea appealed to her.

And we were looking for silver linings because breast reconstruction was not an option for her. Why? Because one of the terminal diseases my sister has is systemic scleroderma . . . her breasts can be cut away, her skin sewn back together over the emptiness, but that same skin isn't like other people's . . . it can't be expected to expand to allow reconstruction.

*I sit and think about my feet on the marred gray concrete, lusting for the soft green grass not too far away. The soft grass whose blades could be folding between my feet and the earth, as a gentle cushion and conduit. But I just sit and think, ten feet from the grass, looking at the comfort instead of taking it. And I think of my sister. My sister and the concrete she has slowly turned into and how mightily she now works to break it up and be who she might have been had the concrete not set in.*

*I think of my surprise of hearing just a few years ago that our favorite uncle had sexually abused her in our youth, so long ago; of how she'd found the courage to tell Mom, who'd said she'd tell Dad, who'd said he'd take care of it.*

*But, somehow, it didn't get taken care of. And Patty's first serious layers of concrete were laid. She had told and it didn't stop, for years. So to her mind her parents didn't protect her. So she started to protect herself surreptitiously with alcohol, then drugs, and a harder and harder shell each year.*

*Call it genetics, call it New-Age-Creating-Your-Own-Disease, call it environmental poisoning from the tainted earth we played on and the toxic water we drank as children*

living on a Superfund site, but, one way or another, the hard attitude she adopted to protect her wounded self became real. She turned to concrete via that remarkably rare systemic scleroderma, where the tissues in your body harden, system by system, until one by one, nothing moves anymore. Your skin turns to Plasticine sheen and shrinks, causing your eyes to look tight. Your lips pull back from your teeth, your joints stop moving, and your fingers start to twist you into sclerodactyly—clawlike hands—because your sheath is no longer flexible.

But aesthetics and the convenience of movement aside, there is great pain as this occurs, and the worst of it is on the inside where the loss of flexibility is a matter of life and death. When scleroderma roots in your lungs, your alveoli no longer expand and contract with each breath—you suffocate. When it lodges in your heart, it will eventually stop beating. Or, like my sister, you might be lucky—if you can call it that—and have it attack first your digestive tract.

You'll live a bit longer that way, and as you wait for it to move to more, shall we say, critical systems, you can suffer through the inability to swallow, through needing your esophagus surgically forced open periodically just to allow space for gravity to pull food, what you can manage of it, to your stomach as you no longer have any peristalsis in your system—your stomach, your bowel, is just a concrete channel.

In my sister's stomach, then, food is not processed well, if at all, depending on her condition at the time. She's had several procedures to remove or dissolve bezoars—the human equivalent of food and mineral hair balls. How she eliminates or doesn't, I'll spare you the details. A few years ago, Patty asked Mom why she hadn't protected her from this uncle Mom had tried. So was it Dad who'd failed? Or had he tried too, ineffectively? The story unfolded, the perpetrator confronted, the confusions cleared up, the healing began. The doctors say she should've been dead long ago, but Patty keeps swinging the hammer at her concrete.

So the silver lining of not being able to have breast reconstruction was that now—if she wanted to, when she was ready, if ever—she could test the waters around, maybe strike a blow for, women's rights. Such a distant possibility, such a

small potential comfort, so who was I—after engendering the idea to start with—to say, “Please put on a shirt” in my home?

And I’m back to wondering, should I go to the Extreme Health conference with her?

This conference—organized by financial guru T. Harv Eker (he went from zero to millionaire in 2.5 years) who boasts of life-changing results in many of his 500,000 students from 80 countries—sounds gimmicky to me. But what do I know? If he could help people with their money that way, maybe he can assemble an inspiring team to help people with their health. Maybe it will hold answers for her. But why do I need to be there? I love her, yet can I commit to the gaze? That is, commit to really focusing on her and her health? It feels safer to just say no to this trip. Yet she asks me for so little than to live with the constant roller coaster of her dramatic health.

Extreme health. If cancer at 40 isn’t extreme enough, if a disease so rare that only 12 to 20 new cases per million people are diagnosed annually isn’t extreme enough, I think to some of the other extreme conditions she has . . . some of the other stops on her journey. Imagine the scene: Patty sits in a cold, sterile doctor’s office. Unusually cold. Suddenly, her fingertips start to turn bluish purple, and as the blood vessels in her fingers, hand, and arm painfully spasm and quit working right, the black-and-blue races up her arm. Her doctor calls the other doctors, nurses, techs, and students in to watch this “classic” episode of Raynaud’s happening in the moment, a rare opportunity and another relatively rare disease. Extreme.

While most people have no autoimmune disease, or only have one, her extreme health finds her with three (at last count). Besides the scleroderma, she also has systemic lupus erythematosus and rheumatoid arthritis. Now, you might think these are just related to the scleroderma or were misdiagnoses on the way to their finding the relatively rarer disease. But, no, she really does have these separate autoimmune diseases piled up on top of each other. Ironically, it is partly due

to her having competing autoimmune diseases that she's held on as long as she has—because while they gang up on her in some ways, in other ways they fight against each other, taking some of the heat off her. I know that's not precise medical talk, but that's the take-home point. Sometimes she'll go into something akin to remission with her scleroderma—basically unheard of except in her! It happens in her case because of the other diseases she has. She's so unique they've written her up in a medical journal.

How did she get here? In retrospect, we think she was showing signs of one or more of these autoimmune diseases early on. For instance, she had great stomach pain and dry heaves since she was five or six. And diarrhea from around the age six or seven. The family, and she herself as she got older, tried different diets and over-the-counter products in response. Eventually the heaves weren't dry, and she started throwing up blood and bile. Some of her symptoms, we've since learned, may have been a red flag for these other conditions. But then maybe not. There was a lot of stress in our family, a lot she figuratively and literally had trouble "stomaching." So maybe that's what led to her digestive issues, including having her gallbladder removed—while leaving a ten-inch scar behind—at the tender age of 21. Who can know now what was really happening then, whether medical or emotional precursors caused her problems—they are both so intertwined anyway.

So this Extreme Health Conference means a lot to her, it seems. Looking for a cure or at least some relief. I imagine hour after hour of conference speakers telling their tales, hawking their products. Are they educating? Or taking advantage of people's fear of illness and death? Or taking advantage of their hope? Or all three? Is there anything wrong with any of that? Do I want to be a part of that? I guess they'd be no different than the medical doctors who do the same.

With my sister, at least, the medicine for one disease often exacerbates another or causes problems of its own. For instance, the steroids they've had her

on too much and too often have caused her to have osteoporosis. Imagine your bones so fragile that you have broken both of your feet—one from simply standing up, the other from having the temerity to take a step. That's her. Extreme. She also broke vertebrae in her neck from simply getting up out of bed (while she was recuperating from her double mastectomy). Screaming in pain, unable to move, she got another trip to the emergency room and yet another neck surgery (three total). Speaking of vertebrae, they've had to insert a stainless steel plate and pins, and something like four Sheetrock screws, and cadaver bones to hold her together. And hold together is what she has done. Given her struggles with this, and I've barely scratched the surface of all she has dealt with, or still deals with, medically.

*My mind flashes back to our childhood and the very weird mole she had on her thigh. Living in the hot desert of Arizona, we were always in shorts, and you really couldn't miss this mole. I remember her crying if it were accidentally scraped while we swam and rough-housed. But it kept growing and changing, un-responded to by our parents until she was at the doctor's office because the hair on her head started to fall out (yet another story), and he insisted it be tested. He feared the worst. And the worst it was—a large malignant melanoma, she might lose her leg. She was only 11. Fortunately, despite how deep and wide they had to go, her leg was preserved.*

Extreme. Extreme Health . . . could this conference make a difference? She wants to go because one of the Dalai Lama's personal physicians will be presenting and consulting there. A Dr. Naram. He's the keeper of ancient scriptures and medical secrets and can describe and diagnose in amazingly detailed ways with a pulse-reading method he learned from an old Indian master. Can he help her with all she has going on? All her complex issues or even the "simple" ones like her gastroesophageal reflux disease (GERD), which has contributed to the erosion of her teeth. Could his herbs and diets help her with the Barrett's esophagus? A condition usually diagnosed in people older than 60, and usually in men; not at all typical for a 40-something woman like my sister. If Dr. Naram could help with



that, it'd be worth the trip as, sadly, Barrett's esophagus is a precursor to cancer of the esophagus. . . . the risk of getting this cancer is 30 to 125 times greater for people with it than for those without.

Her extreme health journey just in childhood was bumpy enough, including two ear surgeries and near death from renal failure at four (unbeknownst until later, she drank a bottle of Lavioris mouthwash that was carelessly left under the sink). And there's a host of other incidents or conditions as an adult, like her experiencing (and thankfully surviving) the extremely rare and extremely scary serotonin syndrome. Imagine suddenly going into seizures so severe and violent that they can't get you into a wheelchair or keep you on a gurney without straps. All because of a rare chemical imbalance in the brain caused by the MDs not paying attention to potential drug interactions. We'd seen her starting to twitch some time before. . . . that, and other signs and symptoms, might have warned us the storm was approaching, but how could we know? Less rare, more predictable, were her painful "female problems," which led to hysterectomy. . . . in thinking back, the year she had her hysterectomy, she had four surgeries in five months. That's a lot for a person to go through and a lot of anesthesia in a short period of time. I remember it took her awhile to think and speak normally after that.

*Extreme Health seems to define my family. With all that, and then some, my sister has suffered, I'd always thought she'd have gone well before my brother. But my brother's disease flared like a shooting star—Jeff died of cancer six short months after diagnosis. In contrast, my sister's constellation is like a black hole that keeps sucking matter; her health problems are like plutonium with a half-life that just won't go away. But any day that star could burn out, and I will wail as if the very sun has died. The second sun, as losing my brother when he was only 42, was huge. Pain or no pain, I'm selfishly glad Patty is still here. She is in and out of the hospital like a drive-thru, and when they move her medical records around, it requires a dolly as they fill three boxes, probably more now.*

Yet I wonder, why should I go to this conference with her? I'm already double booked that week, busy—like everyone—yet Patty persists in wanting me to join

her there. I wouldn't know what to expect from such a conference except for four long sixteen-hour days. I imagine a bunch of odd health zealots getting in my face and insisting that I eat bran or drink rainwater or whatever. I imagine them not letting me out of the room until they've broken me down to admit every time I've eaten fast food—every gram of trans fat—and forced me to agree to give up chocolate. Not my idea of fun. But I could be wrong—they're probably not that demanding and zealous. And she's so sure I should go. I think she worries about my health too. I've had my own challenges. Yet her extreme health journey is not only more varied and dense than my own, it started much earlier.

I remember the stories that Patty started life with a fight. For her to just survive birth was a struggle as she was born breech (feet first, instead of headfirst) and prolapsed (afterbirth comes first, instead of after). One is bad enough; both put her at extreme risk. They were going to do a Caesarean, but suddenly the cord came out, and it turns out it was twisted and wrapped around her neck twice. . . . No time . . . she needed to be born within ten minutes of the output of the cord or she'd suffer from insufficient oxygen. No time for an episiotomy, Mom was torn open to later suffer 55 stitches. Patty was born in 4.5 minutes, thank goodness, but was the color of lead blue.

My sister. So determined from the very start. One of the many things I admire about her—that determination. That courage. Patty lives with pain every day. Every, every day. How does she do it? She doesn't define herself by her illnesses or her pain. That's how. And she balances working with the medical community and pushing away from it at times, to their frustration. But they respect her as she's amazed them with her survival, her positive attitude, her knowledge. That knowledge she's built out of necessity, and now, in many cases, she knows as much or more about her various conditions as they do. She had to learn, again to protect herself, because it took years before she found a doctor who could keep straight all her conditions at once (she calls him her "quarterback") and not do something "to help" that would make something else simultaneously worse in

some unacceptable way. Of course, that does still happen—the trade-offs. And while the MDs may chide her when she sometimes chooses to take back some of the control from them to use acupuncture or Reiki or network chiropractic, or any of the other ideas that may, I imagine, come up at the Extreme Health Conference, they are often surprised with the progress she makes without them. In a world where “progress” is not measured by cure or recovery but only by if you deteriorate more slowly or can kick one of these beasts into remission for a while, rebuild a bit of bone mass, or a variety of other measures scientific and not

*My mind, my heart remembers the emotions and fears I've traveled through with her, or because of her. All the troubles in her life . . . never knowing if this episode, this hospitalization, this drama will be her last. Or, if she will pull through as she has time and again. Over the years, I may have taken too much comfort in her ability to somehow pull through; I may have gotten complacent. I can't be lulled into inaction because of her remarkable resilience. One day, she won't pull through.*

How would she be at this Extreme Health Conference? I have no crystal ball. She may be managing okay that week, or she could be sick in bed the whole time, despite her fervent wish to be at the sessions. I may be splitting time between being her caretaker and going to the sessions alone. What new concern will await her? Or me? It's hard to live with this—with her extreme health. It's hard to look upon her and her suffering, despite her usually cheerful attitude and her smile that defies any darkness. It's hard to live with it, but I know it will be harder to live without it.

The flight to join her at the Extreme Health Conference blinks on my screen, waiting. I hit “submit.”