Hallelujah the Blind Gifts

Katherine E. Standefer

The rash, I come to understand, is not a rash. The white spots—arranged in constellations, like little acid drops flung at the skin—are places my body has lost the ability to produce melanin. Worst on my right shoulder, they sprinkle onto my back; a few grace the neck, a few nestle into chest skin.

Years ago, when I worked as a nude model for plein air landscape artists trying to keep sharp during their long, snowbound Wyoming winters, these were the parts of my body the artists extolled. “Have you ever been told you have wonderful clavicles?” one artist said, dark pencil held aloft, as I turned on the padded stand. Or: “I love your collarbone.” Outside the giant window, walls of snow moved across the valley floor, catching in the aspens, as I bent and stretched and folded. The pellet stove shimmered with heat. I was their Venus, shoulders so broad my dresses tugged open, hips requiring a swivel of the charcoal. In those winters our faces and hands tanned from the glare of sun against snow, while the rest of our bodies paled into banks of white.

That was years ago, in my early twenties, a different life. Now, for the three years I have been running at lunchtime in the ragged mountains outside Tucson, Arizona, my shoulders have had no season of rest. If Venus, I have been one tagged with dark tan lines. Even when I did not love the dogged pace of carrying water on a hip belt, of slogging in hundred-degree heat, I have loved the glow of myself. I have loved how trail running tugs brown muscles from my legs and bleaches my hair thin. Like all privileges, I forgot that this could be lost.

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The strange raised skin began between my breasts, during a research trip to the eastern coast of Madagascar. Back in Tucson, patches crawled my chest. They flared in the sun or when I drank beer. Heat rash, my acupuncturist said. Surface yeast. I ran anyway. A little yeast never killed anyone. It was a year before the spots appeared on my shoulders, the size of peppercorns, and then contact lenses, until where they merged with each other the skin became like a long skim of moonlight over water. I worried I would have to eat a sugar-free diet for months to kill the fungus.

But no: Vitiligo, the nurse practitioner in the basement of the community college said. A dearth of melanin. Beneath the spots, the cells that produce skin pigment had died or stopped functioning. I could expect the spots not only to stay but to grow. To become a blotchy lattice of white across my face or hands. An antifungal would not change this, although one was prescribed for the heat rash between my breasts, which was indeed, it turns out, its own condition.

The vitiligo would not kill me, no, but I spent the next weeks ducking quickly into buildings, driving instead of bike commuting, terrified of making it worse. I wore the same few shoulder-covering shirts, layering my chest and neck with scarves in the heat. I became suddenly aware than my entire wardrobe has been fashioned as a monument to the bronze of my body, my shirts and dresses all sleeveless and low-cut.

It is the Arizona sun the nurse practitioner suspects is to blame for this—the repeated insult of burns and tans. Before I left the clinic, the nurse practitioner lowered her gangly body to eye level, placing her hands firmly on my shoulders. “SUNSCREEN,” she demanded. She warned that this could be the harbinger of autoimmune conditions to come. She warned that I may need treatment with steroids to prevent the spread. And I had flashes of my face suddenly turning white, men startled and disgusted by me, the beauty of youth, of functioning melanocytes, falling away too soon.
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The Parting
Melora Wolff

It is only one more way the body can fail. It is only one more thing to be grateful the body was doing, all these years, unseen until now. Hallelujah the blind gifts, so foundational as to be invisible.

... ... ...

I have lived inside the fold of this invisibility. Growing up, I could see only what was identifiable as struggle. I saw not that my parents protected me from the dark sides of themselves, but that they struggled to protect me from my older sister; I saw not the packs of new markers and white tennis shoes appearing reliably at the start of each school year, but that we packed sack lunches on vacation to save money.

In my own knotty memories, my father is calling the principal weekly to address the matter of the boys who followed me down the hallway, talking loudly about my breasts (the second-biggest tits in the 6th grade, we all knew), kicking my backpack as I walked—those boys pulling the pads and tampons from my backpack and tossing them around the corridor, shrieking.

Today, I understand that my pain was both very real, and outsized in some way. It never occurred to me that other children might be moving ceaselessly, living with their mothers’ terrible boyfriends; that the boyfriends might be the ones making them feel unsafe, or even their own fathers. There could be breasts stroked in darkness, thighs clasped, or worse, and no one was calling on their behalf.

It never occurred to me that the car might break down and not be fixed, that the doctor’s visit could be too expensive to go at all, that Christmas presents required saving. Struggle is a narrative, disruption demands plot; what is working does not. My life hummed along functionally, floated by the fact of our white-ness, our home in a safe suburb of Chicago, and by my father’s salary as an attorney—by his measured, gentle, educated tone, and by a host of his invisible choices, such as using alcohol sparingly. So, too, was I gifted the availability of my mother, who stayed home with us during the years when we might miss her most. Under her eye we made it to school on time, in clean clothes, with sectioned apple in tiny Ziplocs. She scored for the softball team, found my crumpled permission slips at the bottom of the backpack, and made sure we threw out the underwear with holes. She made so much happen. She was invisible; I never saw her.

A good life requires constant upkeep, it turns out, and the underpinnings invisible then are missing now. As an adult I am constantly flummoxed by the baseline difficulty of things. I can cook and clean, but rarely in the same week; simply to pay my bills requires so much of me that the rest of my life tends to fall apart. I lose things, or break things and do not fix them, unless I take a day off work specifically to accomplish this task. God help me when a bike ticket or hospital bill demands logistical attention. (The boon of the rich is not that their lives are inherently easier, but that they can afford to outsource some of the difficulty.)

And this is the work of the body, existing in a constant state of self-repair: each organ cleansing blood or managing salt or sugar, with the cells mounting defenses we never notice, recycling themselves. Our breached skin sews itself. Our bones resist breaking, or knit back together if they must. The body is a city of privilege, if we are young and well. The city moves with a quiet, efficient hum. Its support structures are exquisite, allowing us to ignore our bodies so much of the time. But the privilege of the body eventually splinters for all of us.

And so privilege is always about where our eyes are not drawn. It unfolds in the moments we do not know things are different for others; in privilege, there is an expectation of functionality, if not elegance.

Oh Hallelujah the blind gifts, the foundation of all privilege. Hallelujah what we might call innocence, the idea that before things got fucked up they were once good.

... ... ...

The summer I turned twenty-five, I stopped wearing sunscreen because I thought I would die young. At the time I made the decision, I’d just gotten out of the hospital. A length of IV tubing still dangled from my arm; the fridge I shared with a boyfriend was full of plastic syringes of antibiotics and saline solution. I was tired.

This time, a bacterial infection had flooded my bloodstream, threatening to shut down my organs and planting a small blood clot in my
right lung. But it was the culmination of a year of hospitals. It was the end of a year in which I’d gone into cardiac arrest in a parking lot and had a defibrillator implanted. When I entered Boulder Community Hospital with sepsis, I was still making payments on the last hospital stay, and something inside me buckled.

The myth of modern medical care is that the cure amounts to a form of healing. The opposite is too often true, the cure no less than another trauma, albeit one we are grateful for. The strange faces of nurses in the middle of the night. The burn of the oxygen line in nostrils. The slow pulse of the blood pressure cuff, interrupting sleep; the botched spinal tap, the numbing agent gargled and plastic tube swallowed, injections that burn in the vein. In the hospital, my life seemed continuously to swing away from me, and I scrambled after it, trying blearily to understand the proclamations of the rotating band of hospitalists who appeared in front of me to dictate what would happen to my body.

In the process, my world shrank. Eventual health no longer seemed a given.

So it was one May morning in my fifth hospital stay, when a pharmacist appeared in the doorway, looking tiny and somewhat nervous. She began reading a description of a new medication—a hefty anticoagulant to dissolve my clot. “You’ve already had the first dose,” she said. A nurse, I realized, had come and gone, injecting me without a word.

I would have to come back to the hospital weekly for six months to receive shots of the blood-thinner, she told me, and I would have to avoid activities that could make me fall down, because the drug would make me hemophiliac. Vitamin K was the antidote—so I would have to steer clear of dark leafy greens. “Kale is a very big problem,” she told me.

But after those weeks in the hospital—after my long year plunged into the constant expectation of death—all I wanted was to fall Range and out over the plains. After the rain would come sun, and after the sun would come kale, and I wanted to be browsing the Farmer’s Market, shoving greens into my mouth, then going for raucous runs on the mountainside. I wanted to feel my youth again, the carelessness of scrapes—not be made hemophiliac by a clot-buster that, I would learn, doubled as rat poison, the animals bleeding out in a corner after ingestion. I wanted it, even if it meant I might die.

For the first time I realized I would die either way. “Kale,” I said out loud, “is never a big problem.” And this is what the hospitalists could not understand: that on the edge of health, a twenty-five-year-old might choose not to finish treatment, might choose not to know definitively that the clot was gone. To them, my chance of recovery was nearly perfect. They understood my privilege to be renewable; these young bodies came back. To me, the future had collapsed. My organs were scarred, my lifetime allotment of X-rays spent. I had spent dark hours with my body in that hospital, feeling its fragility, learning that it was capable of rotting alive for no particularly good reason. If the clot had followed sepsis, as sepsis followed heart surgery, as heart surgery had followed cardiac arrest in a parking lot on a random, gorgeous Thursday in June—there would be more of this, guaranteed. My expectation of the privilege of health had evaporated. And if my life was to become a revolving door of hospital stays, I wanted to spend my last days fully immersed in the things I loved best, without distraction.

From this lens, sunscreen was a mighty unnecessary pain in my ass.

It is not that I actually thought I would actually be dead in 6 months—although now that I say it, I remember how every symptom seemed tumorish in its possibility. One morning, less than two months from the day I refused the treatment, I had a shooting pain across my chest, and when it happened again and again, my heart sank: it must be the clot, still there, not dissolved by time and the body’s persistence. I was supposed to be at a conference at a hotel on the river; I texted my supervisor: Headed to the hospital. But once there, the doctor issued a scan that quickly cleared me; the clot in my lung was gone. The pain must have been muscular, a pulled pectoral. I arrived at the conference and spread pads of butter on my bread roll, and forked at the lettuce on my plate, and opened my shiny folder, and my supervisor and
a partnered activity; I am a loner. And the mark of the sun on my body has been so embedded in my sense of my own beauty and health, I could not fully see it until now.

Yet if we are to blame in ways for our ailments, the body was going to wear out anyway—like a favorite pair of shoes, donned so often they lose their tread before all the others. Each of us doesn’t heal, in the constellations that come to mark the body, in an accumulation of conditions. I am old enough to pause before I tell a friend what is happening to me, for fear that blame will be her answer; you should have worn sunscreen. And maybe I have wasted my privilege, that inborn gift of beauty and functionality, a gift not everyone began with.

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And I slide into my car and stare for a moment at the cracked windshield, for I have done all this crying for nothing.

will, in our own particular ways, wear the body thin by the choices we make: living stressed for a larger purpose, inhabiting a beloved smoggy city, reading in the dark, pounding our knees on trails until the cartilage gives. Health is a privilege that not everyone begins with, but it is surely one that every one of us will lose.

The idea of a young death was seductive then. “I won’t live long enough to die of skin cancer,” a 25-year-old version of me told a friend at work; but I couldn’t see then that dying at 39 still counted as young, that even dying at 50 would feel like a loss. While it was reasonable in ways to assume I would not die from the sun’s radiation as absorbed over a lifetime, I could still die from sun combined with all those CT scans and X-rays. “You’ve had too many as a young person,” the doctor said on that day of the conference. And of course all this ignored entirely the possibility of other skin conditions: enter vitiligo.

And so the vitiligo has, as one of its ingredients, this haughtiness about death, this belief that the skin didn’t matter because it was my heart or sepsis that would kill me. In my mid-twenties, I insisted I understood how I would go: I would collapse somewhere, or my defibrillator wire would be yanked bloody from the tissue of my heart in an accident, or I would rot alive by bacteria again. Yet the more I expected my death, the more I minimized it. It became a thing I could know or even control. To embrace death was to live without the terror that was the worst part. I was going to die; I was no longer accountable for how I would live.

I lived, of course. I’m thirty now, which is old enough to begin suspecting the way death really occurs, in fits and starts, in tissue that Single for nearly six years now, I sometimes sob in the mirror at night that no one will love me once my face is marred by white blotches, though this is a lie, of course: the wrinkled, the horribly misshapen, link their arms together on the street every day in front of me. They press their lips together, and rub each others’ crooked backs. I make myself picture a man who will treasure the strange continents of my body, this lick of mortality to my shoulders. I picture him faulted and falling apart, too, and how funny we would be, marred and marked. I work to make another version of the future possible, in my mind. For even if I can come around into loving it—even if I rework my silly youthful definition of beauty—it is not what I always assumed to be my birthright.

And then there is another doctor’s appointment, late in the year, and a dermatologist swings her small lamp across my hands and then my face, peering, her dark braid swinging as she moves. “There’s no way this is vitiligo,” she says simply. “It would start on the hands and the face. It wouldn’t be in circles like this.” She prescribes an antifungal and cautions me not to stop using it for months, because the infection can return, and even when it is clear the skin may take a while to regenerate its melanin.

And I slide into my car and stare for a moment at the cracked windshield, for I have done all this crying for nothing. My shoulders will brown again; my tissues have a lap or two left. But I have remembered the lesson: Hallelujah the blind gifts, so invisible as to be unseen. It is only in the crumbling of my privilege that I see it at all.