

# THE DEVIL'S BAIT

Symptoms, signs, and the riddle of Morgellons

By Leslie Jamison

**F**or Paul, it started with a fishing trip. For Lenny, it was an addict whose knuckles were covered in sores. Dawn found pimples clustered around her swimming goggles. Kendra noticed ingrown hairs. Patricia was attacked by sand flies on a Gulf Coast beach. Sometimes the sickness starts as blisters, or lesions, or itching, or simply a terrible fog settling over the mind, over the world.

For me, Morgellons disease started as a novelty: people said they had a strange ailment, and no one—or hardly anyone—believed them. But there were a lot of them, reportedly 12,000, and their numbers were growing. Their illness manifested in many ways, including fatigue, pain, and formication (a sensation of insects crawling over the skin). But the defining symptom was always the same: fibers emerging from their bodies. Not just fibers but fuzz, specks, and crystals. They didn't know what this stuff was, or where it came from, or why it was there, but they knew—and this

*Leslie Jamison is the author of a novel, *The Gin Closet* (Free Press), and of *The Empathy Exams: Essays, to be published next April* by Graywolf.*



was what mattered, the important word—that it was *real*.

The diagnosis originated with a woman named Mary Leitao. In 2001, she took her toddler son to the doctor because he had sores on his lip that wouldn't go away. He was complaining of bugs under his skin. The first doctor didn't know what to tell her, nor did the second, nor the third. Eventually, they started telling her something she didn't want to hear: that she might be suffering from Münchhausen syndrome by proxy, which causes a parent or caregiver to fabricate (and sometimes induce) illness in a dependent. Leitao came up

with her own diagnosis, and Morgellons was born.

She pulled the name from a treatise written by the seventeenth-century English physician and polymath Sir Thomas Browne, who described

that Endemial Distemper of little Children in Languedock, called the Morgellons, wherein they critically break out with harsh hairs on their Backs, which takes off the unquiet Symptoms of the Disease, and delivers them from Coughs and Convulsions.

Browne's "harsh hairs" were the early ancestors of today's fibers. Photos online show them in red, white, and blue—like the flag—and also black and translucent. These fibers are the kind of thing you describe in relation to other kinds of things: jellyfish or wires, animal fur or taffy candy or a fuzzball off your grandma's sweater. Some are called goldenheads, because they have a golden-colored bulb. Others simply look sinister, technological, tangled.

Patients started bringing these threads and flecks and fuzz to their doctors, storing them in Tupperware or matchboxes, and dermatologists actually developed a term for this phenom-

enon. They called it “the matchbox sign,” an indication that patients had become so determined to prove their disease that they might be willing to produce fake evidence.

By the mid-2000s, Morgellons had become a controversy in earnest. Self-identified patients started calling themselves Morgies and rallying against doctors who diagnosed them with something called delusions of parasitosis (DOP). Major newspapers ran features posing some version of a question raised by the *New York Times* in 2006: “Is It Disease or Delusion?” The Centers for Disease Control and Prevention (CDC) launched a full-scale investigation soon afterward.

In the meantime, an advocacy organization called the Charles E. Holman Foundation started putting together an annual Morgellons conference in Austin, Texas, for patients, researchers, and health-care providers—basically, anyone who gave a damn. The foundation was named for a man who devoted the last years of his life to investigating the causes of his wife’s disease. His widow runs the conference. She’s still sick. The conference offers Morgies refuge from a world that generally refuses to accept their account of why they suffer. As one presenter wrote to me:

It is bad enough that people are suffering so terribly. But to be the topic of seemingly the biggest joke in the world is way too much for sick people to bear. It is amazing to me that more people with this dreadful illness do not commit suicide . . .

The CDC finally released its study, “Clinical, Epidemiologic, Histopathologic and Molecular Features of an Unexplained Dermopathy,” in January 2012. Its authors, in association with the so-called Unexplained Dermopathy Task Force, had investigated 115 patients, using skin samples, blood tests, and neurocognitive exams. Their report offered little comfort to Morgellons patients looking for affirmation:

We were not able to conclude based on this study whether this unexplained dermatopathy represents a new

condition . . . or wider recognition of an existing condition such as delusional infestation.

The authors suggested, with some delicacy, that patients might be treated for a number of “co-existing conditions,” such as drug abuse and psychosomatic disorders.

The bottom line? Probably nothing there.

**T**he Westoak Woods Baptist Church, on Slaughter Lane, is a few miles south of the Austin I’d imagined, an Austin full of Airstream trailers selling gourmet doughnuts, vintage shops crammed with taxidermied animal heads and lace, melancholy guitar riffs floating from ironic cowboy bars. Slaughter Lane is something else. It’s Walgreens and Denny’s and eventually a parking lot sliced by the spindly shadow of a twenty-foot-tall cross.

The church itself is a low blue building. A banner for the 2012 conference reads: *SEARCHING FOR THE UNCOMMON THREAD*. By the entrance, a cluster of friendly women greet new arrivals. On each of their matching shirts, the letters DOP are slashed out in red. Most of the participants at the conference, I will come to realize, give the wholesome, welcoming impression of no-nonsense Midwestern housewives. I will also learn that 70 percent of Morgellons patients are female—and that women are especially vulnerable to the isolating disfigurement and condescension that accompany the disease.

The greeters direct me past an elaborate buffet of packaged pastries and into the sanctuary, which is serving as the main conference room. Speakers stand at the pulpit with their PowerPoint slides projected onto a screen behind them. Each cloth-covered pew holds a single box of Kleenex. The room has one stained-glass window—a dark-blue circle holding the milky cataract of a dove—but its panes admit no light.

This gathering is something like a meeting of alcoholics or Quakers. Between speakers, people occasionally just walk up to the pulpit and start sharing. Or else they do it in their chairs, hunched over to get a

better look at one another’s limbs. They swap cell phone photos. I hear people talk about drinking Borax and running sound waves through their feet, about getting the disease from their fathers and giving it to their sons. I hear someone talk about what her skin is “expressing.” I hear someone say, “It’s a lonely world.”

I discover that the people who can’t help whispering during lectures are the ones I most want to talk to; that the coffee station is useful because it’s a good place to meet people, and also because drinking coffee means I’ll have to keep going to the bathroom, which is an even better place to meet people. The people I meet don’t at first glance look disfigured. But up close, they reveal all kinds of scars and bumps and scabs.

I meet Dawn, a nurse from Pittsburgh, whose legs show the white patches I’ve come to recognize as formerly scabbed or lesion-ridden skin. Antibiotics have left a pattern of dark patches on her calves that once got her mistaken for an AIDS patient. Since her Morgellons diagnosis, Dawn has continued working.

“I was so angry at the misdiagnoses for so many years,” she says, “being told that it was anxiety, in my head, female stuff. So I tried to spin that anger into something positive. I got my graduate degree. I published an article in a nursing journal.”

I ask her about this phrase, “female stuff.” It’s like heart disease, she explains. For a long time, women’s heart attacks were misdiagnosed or even ignored because doctors assumed that these patients were simply anxious or overly emotional. I realize Dawn’s disease has been consistently, quietly embedded in a tradition that goes all the way back to nineteenth-century hysteria. She says her co-workers—the nurses, not the doctors—have been remarkably empathetic. Now they come to her whenever they find something strange or unexpected in a wound. She’s become an expert in the inexplicable.

I ask Dawn what the hardest part of her disease has been. At first she replies in hesitant, general terms—“Uncertain future?”—but soon

she settles on a more specific fear. "With the scars and stuff that I have from this," she says, "what guy's gonna like me?"

When Dawn talks about her body as something that's done her wrong, I fall into the easy groove of identification. Her condition seems like a crystallization of what I've always felt about myself—a wrongness in my being that I could never name and so pinned on my body, my thighs, my face. This resonance is part of what compels me about Morgellons.

But my willingness to turn Morgellons into metaphor—a physical manifestation of some abstract human tendency—is dangerous. It obscures the particular and unbidden nature of the suffering in front of me. I feel how conveniently these lives could be sculpted to fit the metaphoric strictures of the essay itself.

**I** once had a specimen of my own. It was a worm in my ankle—a botfly larva from Bolivia—that was too far under the skin to see. I remember my voice in the Yale–New Haven ER saying, "There's a worm," and I remember how everyone looked at me: kindly and without belief. Their doubt was like humidity in the air. They asked if I'd recently taken any mind-altering drugs. The disconnect felt even worse than the worm itself—to live in a world where this thing *was*, while other people lived in a world where it wasn't.

It was almost a relief to finally see the worm, bobbing out of my ankle like a tiny white snorkel. I finally knew it was real. It's the Desdemona Problem facing Othello: fearing the worst is worse than knowing the worst. You eventually start *wanting* the worst to happen.

I still remember the shrill intensity of my gratitude when a doctor verified the worm's existence. Desdemona really had fucked Cassio. It was a relief. The doctor pulled out the worm and gave it to me in a jar. The simultaneity was glorious: the worm was gone and I'd been right about it. I had about thirty minutes of peace before I started suspecting there might be another one.

I spent the next few weeks obsessed with the open wound on my ankle, looking for signs of a remaining worm. None emerged, but I didn't give up looking. Maybe the worm was tricky. It had seen what had happened to its comrade. I inspected the incision relentlessly for signs of eggs or movement. Anything I found was proof: a stray bit of Band-Aid, a glossy patch of bruised skin or scab.

It's easy to forget how Sir Thomas Browne insisted on the value of those "harsh hairs" covering the backs of his Languedoc urchins. He suggested that these strange growths quelled the "unquiet Symptoms of the Disease." Which is to say: physical symptoms can offer their own form of relief—they make suffering visible.

I don't know what causes the pain of Morgellons, the rustling on the skin, the threads and lesions. I only know what I learned from my botfly and its ghost: it was worse when I didn't have the worm than when I did.

**A** woman named Kendra, from Memphis, called a Morgellons hotline thinking she might be crazy. Now she's here at the conference. She sits on the church steps and smokes a cigarette. She says she probably shouldn't be smoking—gesturing at the church, and then at her scarred face.

Her cheeks show sores covered with pancake makeup. But she's pretty and young, with long, dark hair and a purple boatneck shirt that makes her look like she's headed somewhere else—the swimming pool, maybe—not back into a dim Baptist church to talk about what's living under her skin.

She says the scientific presentations have all gone over her head, but that she's looking forward to tomorrow's program, an interactive session with a high-powered microscope. That's why she came all this way. She's seen things—what she initially mistook for hairs and now thinks are fibers—but the microscope will see more. She'll get proof. She can't get it anywhere else. She doesn't have medical insurance, and doctors don't believe her anyway. "I've messed with a part of my chin,"

she confesses. "It's almost like trying to pull out a piece of glass." Something raw and reddish has been chalked with beige powder.

She makes a point of telling me she never had acne as a teenager. She wasn't one of the facially marred until suddenly she was. Now, at the conference, she's among others like her, and this helps.

Folie à deux is the clinical name for shared delusion. Morgellons patients all know the phrase—it's the name of the crime they're charged with. But if folie à deux is happening at the conference, it's happening en masse: an entire churchful of folks having the same nightmare.

I ask Kendra if she ever doubts herself. Maybe she's afraid of something that's not actually happening?

"It's a possibility," she says, nodding. "But at the same time, you know, I think I've got a pretty good head on my shoulders. I don't think I've totally lost all my marbles."

She admits that coming here has made her a little bit afraid. In two years, will she be showing up in the emergency room with all the skin peeled off her chin? Spitting up bugs in the shower? In twenty years, will she still find her days consumed by this disease?

"Everyone who is born holds dual citizenship," Susan Sontag writes, "in the kingdom of the well and in the kingdom of the sick." Most people live in the former until they are forced—for certain spells of time—to take up residence in the latter. Right now Kendra is living in both. She tells me she's meeting a friend downtown for sushi tonight. She can still understand herself outside the context of this disease: someone who does ordinary things, looks forward to the events of an ordinary life.

But Kendra feels a growing affinity with this community, the refuge and consolation that it offers.

"We can't all be delusional," she says.

**B**efore the afternoon session begins, we get a musical interlude. A young man wearing jeans and flannel—somebody's Texan nephew-in-law—performs a rockabilly song about Morgellons. "We'll guarantee



you tears and applause," he sings. "Just take on our cause." It seems like he's only doing this as a favor to his wife's step-aunt. Yet he launches bravely into each new song, most of them some combination of battle cry, rain dance, punch line, lament. "Doctor, doctor, won't you tell me what's the matter with me?" he sings. "I got things going wild in my body, can't you see?"

The star of the session is a physician from Laurieton, New South Wales, known casually around the conference as "the Australian." In his talk, he responds directly to the recent CDC report, which he calls a "load of hogwash" and a "rocking-horse-dung pile." He contrasts the good guys (doctors who listen) with the bad guys (doctors who don't). The Australian listens. He is one of the good guys.

He aims to get the crowd fired up, and he succeeds. He offers himself to the room as a fighter. He coins a new piece of jargon: DOD, for delusions of doctors. This gets applause and a couple of hoots from the back.

The Australian might be an egomaniac or a savior, probably both. But what matters is the collective nerve he hits, the specter he summons—of countless fruitless visits to countless callous doctors. One senses a hundred identical wounds across this room. Not just from glass and fibers but also from smirks and muttered remarks, hastily scribbled notes, cutting gazes. I'm moved less by the mudslinging than by the sense of liberation underneath the crowd's applause.

**T**his isn't an essay about whether Morgellons disease is real. That's probably obvious by now. It's an essay about what kinds of reality are considered prerequisites for compassion. It's about this strange sympathetic limbo: Is it wrong to speak of empathy when you trust the fact of suffering but not the source?

Calling Morgellons "real" generally means acknowledging there is actual, inexplicable stuff coming up through human skin. "Real" means a fungus, parasite, bacterium, or virus—anything that might persuade the skeptical medical establishment

that these patients aren't simply making the whole thing up.

The notion of "making it up" is also complicated, and could mean anything from intentional fabrication to hypochondria to an itch-scratch cycle that's gotten out of hand. Itching is powerful: the impulse that tells someone to scratch lights up the same neural pathways as chemical addiction. An itch that starts in the brain feels just like an itch on the skin, and it can begin with something as simple as a thought. It can begin from reading a paragraph like this one. Itching is a feedback loop, and it testifies to the possibility of symptoms that dwell in a charged and uneasy space between body and mind.

That's why "self-excoriation" is such a taboo phrase here, and why patients are so deeply offended by any accusation that they've planted fibers in their own skin. These explanations pin the blame back on *them*, suggesting not only that the harm inflicted is less real, but also that it's less deserving of compassion or aid. In contrast, parasites and bacteria are agents of otherness, granting the legitimacy of external struggle.

This insistence on an external source of damage implies that the self is a single coherent entity, a unified collection of physical, mental, and spiritual components. When really, the self—at least as I've experienced mine—is much more discordant and self-sabotaging, neither fully integrated nor consistently serving its own good.

During one discussion of possible bacterial causes of Morgellons, a woman raises her hand to make what initially seems like an incongruous point. "Maybe there *are* no autoimmune diseases," she says. "They just don't make sense." Why, after all, would a body fight itself? Perhaps, she suggests, what seems like an autoimmune disorder is simply the body anticipating a foreign invader that hasn't yet arrived. This logic, too, is predicated on a vision of the self as a whole, united, its parts working in concert—yet it betrays a lurking sense of the body's treachery, a sense of sickness as mutiny.

# Turning Toward Home

## REFLECTIONS ON THE FAMILY FROM HARPER'S MAGAZINE

Some of our most loving—and most difficult—relationships are with our parents, children, siblings, and extended families. These complicated relationships are the foundation of our society and our lives: they define our past, give us hope for the future, teach us to get along with others, and, often, provide excellent examples of how not to behave. The moving essays in *Turning Toward Home*, all of which were originally published in *Harper's Magazine*, gracefully explore these dynamics. Authors include David Mamet, Donna Tartt, Richard Ford, Sallie Tisdale, Louise Erdrich, and many more. Introduction by Verlyn Klinkenborg.

Order today through  
[www.harpers.org/store](http://www.harpers.org/store)

Published by Franklin Square Press

ISBN 1-879957-08-6

Softcover \$14.95

FRANKLIN  
SQUARE  
PRESS



Distributed through  
Midpoint Trade Books

What does it look like when the self fights itself? When a human being is broken into warring factions? Perhaps it looks like the experimental cures I see here: scraping or freezing the skin, hitting it with lasers or defibrillators, dousing it with acid or lighter fluid, taking cocktails of anti-parasitic medicines meant for animals three times our size.

But I wonder why this fracturing of the self shouldn't warrant our compassion just as much as a diseased body. Or maybe even more.

**I** duck out of the second afternoon session and fall into conversation with two men involved in a tense exchange near the cookie tray. Paul is a blond Texan wearing a silver-studded belt and stiff jeans. Lenny is from Oklahoma, a well-coiffed man with a curled mustache and a dark tan. Both wear flannel shirts tucked into their pants.

Paul is a patient, and Lenny is not. Lenny's here because he thinks he may have found the cure. A woman came to him with the disease all over her knuckles and he treated it with a laser. "I turned it on that," he says, "and it killed it."

I ask if he's a dermatologist.

"Oh no!" he says. "I'm an electrician."

This woman had two years of pain, Lenny says, and nothing helped her until he did. About twenty minutes into the conversation, he also mentions she was a meth addict. He assures us that his laser cleaned her out until there was "no sign left" of any fibers. Paul has a strange look on his face as Lenny describes the cure. "You didn't heal her," he says finally. "It's a virus."

Lenny nods, but he's clearly taken aback. He wasn't expecting resistance.

"I've been dealing with this for eight years," Paul continues. "And I would've chopped off my hand if that would have stopped it from spreading to the rest of my body."

Paul looks worse than anyone else I've seen. He has his own name for his illness—the Devil's Fishing Bait—because, he says, he got it on a fishing trip. Sometimes he refers to it as a virus, other times as a parasitic infestation, but the sense of sinister agency remains the same.

Paul's disease is different in that you can see it. His right ear is the most obvious sign of his affliction. It's a little twisted, almost mashed, and it has the smooth, shiny texture of scar tissue all along the juncture between ear and jaw. His face is dotted with red pockmarks; the skin is stained with milky patterns, and he's got teardrop scars around his eyes.

Paul says he came home from the fishing trip with his legs covered in chigger bites. "You could feel the heat coming out of my pants," he says. His whole body was inflamed. I ask about his symptoms now. He simply shakes his head: "You can never tell what's coming next."

I ask whether he gets support from anyone in his life. He does, he says. That's when he tells me about his sister.

At first, she wasn't sympathetic. She assumed Paul was on drugs when he told her about his symptoms. But she was the one who eventually discovered Morgellons, just about a year ago, and told him about it.

"So she's become a source of support?" I ask.

"Well," he says. "Now she has it, too."

They experiment with different treatments and compare notes: freezing, insecticides, dewormers for cattle, horses, dogs. A liquid-nitrogen compound he injected into his ear. Lately, he says, he's had success with root beer. He pours it over his head, his face, his limbs. He tells me about arriving at the ER one night with blood gushing from his ear, screaming because he could feel them—*them* again, uttered with such force—tearing him up inside. One of the ER doctors did a physical examination and noted that his mouth was dry. Paul told the doctor it was from shouting at them for help.

Paul doesn't seem overly impressed with the conference. Mainly because it hasn't offered up a cure, he says, though there's a trace of satisfaction in his disappointment, as if certain suspicions have been confirmed.

I sit behind him during the day's final presentation. I can see he isn't paying attention to the speaker. He's looking at photographs on his computer. They're all images of his face,

mostly in profile, focused on his ear. He shows them to the middle-aged woman sitting beside him, and points to a photo of a small metal implement that looks like a pair of tongs: a taser. A few moments later, I hear him whisper, "These were all eggs."

**W**hen I leave the church, I find sunlight waiting outside our windowless rooms. The world has been patient. Springtime in Austin is grackles in the trees; a nearly invisible fluttering of bats under the Congress Avenue Bridge and a waft of guano in blue-washed twilight. Austin is beautiful women everywhere, in scarves and boots, and wind-blown oak leaves skittering across patios where I eat oysters on ice. People with narrative tattoos smoke in the heat. I find a grotto dedicated to the Virgin Mary with an empty beer bottle and a bag of Cheez-Its buried in the gravel.

I walk among the young and healthy and I am more or less one of them. I am trying not to itch. I am trying not to take my skin for granted. But I can't quiet the voices of those who no longer feel they belong anywhere. I spend a day in their kingdom and then leave when I please. It feels like a betrayal to come up for air.

**D**oubting the existence of Morgellons hasn't stopped me from being afraid I'll get it. Before the conference, I told my friends: "If I come back from Austin thinking I have Morgellons, you have to tell me I don't." Now that I'm here, I wash my hands a lot. I'm conscious of other people's bodies.

Then it starts happening, as I knew it would. After a shower, I notice small blue strands like tiny worms across my clavicle. I find what appear to be minuscule spines, little quills, tucked into the crevice of a fortune line on my palm.

If you look closely enough, of course, skin is always foreign—full of bumps, botched hairs, hefty freckles, rough patches. The blue fibers are probably just stray threads from a towel, or from my sleeve, the quills not quills at all but smeared ink on

the surface of the skin. But it's in these moments of fear that I come closest to experiencing Morgellons the way patients do. Inhabiting their perspective only makes me want to protect myself from what they have. I wonder if these are the only options available to my crippled organs of compassion: I'm either full of disbelief or I'm washing my hands in the bathroom.

I'm not the only person at the conference thinking about contagion. One woman stands up to say she needs to know the facts about how Morgellons is really transmitted. She tells the crowd that her family and friends refuse to come to her apartment. She needs proof they can't catch the disease from her couch. It's hard not to speculate. Maybe her family and friends are afraid of catching her disease—or maybe they're keeping their distance from what they understand as her obsession.

Kendra tells me she's afraid of getting her friends sick whenever she goes out to dinner with them. I picture her at the sushi place—handling her chopsticks so carefully, keeping her wasabi under strict quarantine, so that this *thing* in her won't get into anyone else.

The specter of contagion serves a curious double function. On the one hand, as with Kendra, there is a sense of shame at oneself as a potential carrier of infection. But on the other hand, the possibility of spreading this disease also suggests that it's real—that it could be proven to exist by its manifestation in others.

This double-edged sword of fear and confirmation is on full display at the Pets with Morgellons website, one of the oddest corners of the Morgellons online labyrinth. In a typical entry, a cat named Ika introduces herself and her illness:

I have been named [for] the Japanese snack of dried cuttlefish.... Typically I am full of chaotic energy, however lately I have been feeling quite lethargic and VERY itchy. My best friend/mommy thinks that she gave me her skin condition, and she is so very SAD. I think she is even more sad that she passed it on to me than the fact that she has it covering her entire face.

The litany of sick animals continues. A sleek white dog named Jazzy sports itchy paws; two bloodhounds are biting invisible fleas; a Lhasa apso joins his owner for stretches in an infrared sauna. Another entry is an elegy for an Akita named Sinbad:

It appears that I got the disease at the same time that my beautiful lady owner got it. And after many trips to the vet they had to put me down. I know it was for my own good, but I do miss them a lot. I can still see my master's face, right up close to mine, when the doc put me to sleep.... I could sniff his breath and feel the pain in his eyes as tears rolled down his face. But, it's ok. I'm alright now. The maddening itching is finally over. I'm finally at peace.

Who knows what happened to Sinbad? Maybe he really did need to get put down; maybe he was old, or sick with something else. Maybe he wasn't sick at all. But he has become part of an illness narrative—like lesions, or divorces, or the fibers themselves. He is irrefutable proof that suffering has happened, that things have been lost.

**T**he second day of the conference kicks off with a Japanese television documentary about Morgellons—known over there as cotton-erupting disease. We see a woman standing at her kitchen counter, mixing a livestock anti-parasitic called ivermectin into a glass of water. The Japanese voice-over sounds concerned, and a conference participant reads an English translation: the woman knows this drug isn't for human consumption, but she's using it anyway. She's desperate. We see a map of America with patches of known cases breaking out like lesions over the land, a twisted manifest destiny.

Just as fibers attach to an open wound—its wet surface a kind of glue—so does the notion of disease function as an adhesive, gathering anything we can't understand, anything that hurts, anything that will stick. "Transmission by Internet," some skeptics claim about Morgellons: message boards as Pied Pipers, calling all comers. It's true that the

Internet made it possible for knowledge of Morgellons to spread, and transformed its sufferers into a self-contained online community.

A woman named Sandra pulls out her cell phone to show me a photo of something she coughed up. It looks like a little albino shrimp. She thinks it's a larva. She photographed it through a jeweler's loupe. She wants a microscope but doesn't have one yet. She put the larva on a book to provide a sense of scale. I try to get a good look at the print; I'm curious about what she was reading.

Sandra has a theory about the fibers—that the organisms inside her are gathering materials to make their cocoons. This explains why so many of the fibers turn out to be ordinary kinds of thread, dog hair, or cotton. Creatures are making a nest of her body, using the ordinary materials of her life to build a home inside her.

Once I've squinted long enough at the shrimpish thing, Sandra brings up a video of herself in the bathtub. "These are way beyond fibers," she promises. Only her feet are visible, protruding through the surface of the water. The quality is grainy, but it appears the bath is full of wriggling larvae. Their forms are hard to feel sure about—everything is dim and a little sludgy—but that's what it looks like. She says that a couple of years ago, there were hundreds coming out of her skin. It's gotten a little better. These days when she takes a bath, only two or three come out.

I'm at a loss. I don't know whether what I'm seeing are worms, or where they come from, or what they might be if they're *not* worms, or whether I want them to be worms or not, or what I have to believe about this woman if they aren't worms—or about the world, or human bodies, or this disease, if they *are*. I do know that I see a bunch of little wriggling shadows, and for now I'm glad I'm not a doctor or a scientist, because leaning into this uncertainty lets me believe her without needing to confirm my belief. I can dwell with her—for just a moment, at least—in the possibility of those worms, in that horror.

I catch sight of Kendra watching Sandra's phone. She's wondering if this is what her future holds. I want to comfort her, to insist that everyone's disease turns out a little different. She tells me about sushi last night: it was good. Turns out she bought a painting. She shouldn't have, she says. She can't afford it. But she saw it hanging at the restaurant and couldn't resist. She shows me a picture on her phone: lush, braided swirls of oil paint curl from the corners of a parchment-colored square.

I think but don't say: fibers.

"You know," she says, voice lowered. "It reminds me a little of those things."

I get a sinking feeling. It's that moment in a movie when the illness spreads beyond its quarantine. Even when Kendra leaves this kingdom of the sick, she finds sickness waiting patiently for her on the other side. She pays \$300 she can't afford just so

she can take its portrait home with her.

**T**he organizers are holding a lottery to give away some inexpensive microscopes: a handful of miniature ones like small black plums, and their larger cousin the EyeClops, a children's toy. I win a mini, but I'm sheepish as I head up to the stage to claim it. What do I need a scope for? I'm here to write about how other people need scopes. Everyone knows this. I'm given a small, square box. I imagine how the scene will play out later tonight: examining my skin in the stale privacy of my hotel room, facing that razor's edge between skepticism and fear by way of the little widget in my palm.

I give my miniscope to Sandra. I give it to her because she is sick of using her jeweler's loupe, because she is sad she didn't get one, and because I feel self-conscious about winning one when I wasn't even looking for fibers in the first place.

"That's so generous," she says.

But maybe it wasn't generous. Maybe it was the opposite. Maybe I'd just taken hours of her life away and replaced them with hours spent at the peephole of that microscope, staring at what she wouldn't be able to cure.

"I can be myself only when I'm here" is something I heard more than once at Westoak. But every time I left the church, I found myself wishing these patients could also be themselves elsewhere, could be themselves anywhere. I think of Kendra, terrified by the same assurances that offered her validation. She had proof of fibers in her skin but no hope of getting them out, only a vision of what it might look like to be consumed by this disease entirely—a thousand bloody photographs on a laptop, or a soup of larvae on her phone.

A confession: I left the conference early. I actually, embarrassingly, went to sit by the shitty hotel pool. I baked bare-skinned in the Texas sun, and I watched a woman from the conference come outside and carefully lay her own body, fully clothed, across a reclining chair in the shade.

**I**'ve left the kingdom of the ill. Dawn and Kendra and Paul and Sandra remain. But I still feel the ache of an uncanny proximity. "Some of these things I'm trying to get out," Kendra told me, "it's like they move away from me." Sometimes we're all trying to purge something, and what we're trying to purge resists our efforts. These demons belong to all of us: an obsession with our boundaries and visible shapes, a fear of invasion or contamination, an understanding of ourselves as perpetually misunderstood.

But doesn't this search for meaning obfuscate the illness itself? It's another kind of bait, another tied-and-painted fly: the notion that if we understand something well enough, we can make it go away.

Everyone I met at the conference was kind. They offered their warmth to me and to one another. I was a visitor to what they knew, but I have been a citizen at times, and I know I'll be one again. Now my skepticism feels like a violation of some collective trust. The same researcher who told me about "the biggest joke in the world" also told me this: "When I heard of your interest, I felt genuine hope that the real story would be told accurately and sensitively." I

can't forget this hope. I don't want to betray it.

"Sit down before fact as a little child," wrote the nineteenth-century biologist Thomas Huxley, in a passage quoted by one of the speakers at Westoak, "and be prepared to give up every preconceived notion, follow humbly wherever and to whatever abyss Nature leads, or you shall learn nothing."

I want to follow humbly; I want to believe everyone. But belief isn't the same thing as compassion, or sorrow, or pity. It wasn't until the seventeenth century that the words *pity* and *piety* were completely distinguished. And what I feel toward this disorder is a kind of piety—an obligation to pay homage, or at least accord some reverence to these patients' collective understanding of what makes them hurt. Maybe it's a kind of sympathetic infection: this need to go-along-with, to nod-along-with, to agree.

Paul said, "I wouldn't tell anyone my crazy-ass symptoms." But he told them to me. He's always been met with disbelief. He called it "typical." Now I'm haunted by that word. For Paul, life has become a pattern and the moral of that pattern is: You're destined for this. The disbelief of others is inevitable and so is loneliness; both are just as much a part of this disease as any fiber, any speck or crystal or parasite.

I went to Austin because I wanted to be a different kind of listener than these patients had generally known: doctors winking at their residents, friends biting their lips, skeptics smiling in smug bewilderment. But wanting to be different doesn't make you so. Paul told me his crazy-ass symptoms and I didn't believe him. Or at least, I didn't believe him the way he wanted to be believed. I didn't believe there were parasites laying thousands of eggs under his skin, but I did believe he suffered as if there were. Which was typical. I was typical. In writing this essay, how am I doing something he wouldn't understand as betrayal? I want to say, I heard you. To say: I pass no judgments. But I can't say these things to him. So instead I say this: I think he can heal. I hope he does. ■