

Subject: Morgellons. Part 2.

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Date: 14/05/2011, 06:32

Newsgroups: alt.conspiracy.area-51

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13, 2011.

May

This talks about a convention of people who have and study Morgellons.

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Many of the attendees have been diagnosed with DOP, a subject that enrages one of the first speakers - Dr Greg S-ith, a paediatrician 28 years' experience. "Excuse me, people!" he says. "This is morally and ethically wrong! So let me make a p-litical statement, boys and girls." He pulls off his jumper, to reveal a T-shirt reading, "DOP" with a red line through it. "No more!" he shouts above wild applause. "No more!"

Later, Sm-th tells me he's been a sufferer since 2004. "I put a sweatshirt I'd been wearing in the garden over my arm and there was this intense burning, sticking sensation. I thought it was cactus spines. I began picking to get them out, but it wasn't long before it was all over my body." He describes "almost an obsession. You just can't stop picking. You feel the sensation of something that's trying to come out of your skin. You've just got to get in there. And there's this sense of incredible release when you get something out."

Smit-'s exposed skin is covered in waxy scars. Although he still itches, his lesions appear to have healed. If, as morgellons patients believe, the sores are not self-inflicted but caused by fibre-creating parasites, how is this possible? "I absolutely positively stopped picking," he says.

That evening, at a nearby Mexican restaurant, I meet Margot, a midwife from Ramsgate who has resorted to bathing in bleach to rid herself of morgellons. She describes how, armed with times-three magnification spectacles, a magnifying glass and a nit comb, she scraped "black specks" from her hair and face on to sticky labels and took them to a dermatologist. She was diagnosed with DOP. "I'm a midwife," she says. "I take urine samples and b-ood specimens. So I was taking them a specimen. That's what wrecked my life and career."

Next, I corner Randy W-more. He is a slim man with a charcoal shirt, orange tie and neatly squared goatee. "We have not yet exactly replicated the exact results of the forensics people in Tulsa," he admits. So far, the laboratory has found Wy-ore's various morgellons fibres to be: nylon; cotton; a blond human hair; a fungal fibre; a rodent hair; and down, most likely from geese or ducks.

"That's disappointing," I say.

He leans his head to one side and smiles. "It is, for the most part, disappointing, but there was a bunch of cellulose that didn't make sense on one. And another was unknown." There's a pause. "Well, they said it was a 'big fungal fibre', but they weren't completely convinced."

The next day, nursing practitioner Dr Ginger S-vely, who claims to have treated more than 500 morgellons patients, leads an informal discussion in the conference room. Around large circular tables sit the dismissed and the angry. "I've seen a fibre go into my glasses," says one. "I've seen one burrow into a pad," adds another. "One of my d-ctors thinks it's nanotechnology"; "I was attacked by a swarm of some type of tiny wasps that seemed to inject parts of their bodies under my skin"; "They have bugs on public transport. Never put your suitcase on the floor of a train."

A furious woman with a big scar on her jaw says, "I have Erin

B-ockovich's lawyer's number in my purse. Don't you think I'm not going to use it."

"But who are you going to sue?" asks a frail, elderly lady two tables away.

The morgellons believers look expectantly at the indignant litigant. "I don't know," she says.

In a far corner, a woman with a round plaster covering a dry, pinkly scrubbed cheek weeps.

I retire to the lobby to await my allotted chat with Sav-ly. I become aware of a commotion at reception. One of the attendees is complaining loudly: "It's disgusting! Bugs! In the bed. I've already been in two rooms".

When she's gone, I ask the receptionist if, over the weekend, there has been a surge in complaints about cleanliness. "Oh yeah." She leans forward and whispers conspiratorially. "I think it's part of their condition."

Yet, when we speak, Savel- is resolute. "These people are not crazy," she insists. "They're good, solid people who have been dealt a bad lot."

A woman approaches the vending machine behind -avely. Between her hand and the handle of her walking stick is a layer of tissue paper.

There is an element of craziness, I suggest.

"OK, there is," she says, "but it's understandable. For people to say you're delusional is very anxiety-provoking. Then they get depressed. Who wouldn't? The next stage is usually an obsessive-compulsive thing - paying attention to the body in great detail. But, again, I feel this is understandable, in the circumstances."

I slip back into the conference room, where Margot is using her 3700 Wi-Fi iPad telescope to examine herself. I have an idea.

"Can I have a go?"

Pushing the lens into my palm, I immediately see a fibre. The group around me falls into a hush. "Did you clean your hand?" Margot asks. She fetches an antibacterial wet-wipe. I scrub and try again. I find an even bigger fibre. I wipe for a second time. And find another one. Margot looks up at me with wet, sorry eyes. "Are you worried?" She puts a comforting hand on my arm. "Oh, don't be worried, Will. I'm sure you haven't got it."

Back in London, I find a 2008 paper on morgellons in the journal Dermatologic Therapy that describes patients picking "at their skin continuously in order to 'extract' an organism"; "obsessive cleaning rituals, showering often" and individuals going "to many physicians, such as infectious disease specialists and dermatologists" - all behaviours "consistent with DOP". (For treatment, the authors recommend prescribing a benign antiparasitic ointment to build trust, and supplementing it with an antipsychotic.) After finding "fibres" on my own hand, I'm fairly satisfied morgellons is some 21st-century genre of OCD spread through the internet and the fibres are - as Wy-ore's labs report - particles of everyday, miscellaneous stuff: cotton, human hair, rat hair and so on.

There is one element of the condition that's been niggling, though. Both Paul and Greg's morgellons began with an explosion of itching. Now it's affecting me: the night after my meeting with Paul, I couldn't sleep for itching. I had two showers before bed and another in the morning. All through the convention, I am tormented; driven to senseless scratching. Why is it so itchy?

I contact Dr Anne Louise O-klander, associate professor at Harvard Medical School and perhaps the only neurologist in the world to specialise in itch. I email her describing morgellons, pointing out it's probably some form of DOP. But when we speak, she knows all about morgellons already. "In my experience, morgellons patients are doing the best they can to make sense of symptoms that are real. They're suffering from a chronic

disorder that's undiagnosed. They have been maltreated by the medical establishment. And you are welcome to quote me on that," she adds.

In 1987, German researchers found itch wasn't simply the weak form of pain it had always been assumed to be. Rather, they concluded itch has its own separate and dedicated network of nerves. And while a pain nerve has a sensory jurisdiction of roughly a millimetre, an itch nerve can pick up disturbances on the skin over three inches away.

Oaklander surmises that itch evolved as a way for humans instinctively to rid themselves of dangerous insects. When a mosquito lands on your arm and it tickles, this sensation is not the straightforward feeling of its legs pushing on your skin. It is, in fact, a neurological alarm system; one that can go wrong for a variety of reasons - shingles, sciatica, spinal cord tumours or lesions, to name a few. In some cases, it can be triggered, suddenly and severely, without anything touching the skin.

This, Oaklander believes, is what is happening to morgellons patients. "That they have insects on them is a very reasonable conclusion because, to them, it feels no different from how it would if there were insects on them. To your brain, it's exactly the same. So you need to look at what's going on with their nerves. Unfortunately, what can happen is a dermatologist fails to find an explanation and jumps to a psychiatric one."

That's not to say there aren't some patients whose problem is psychiatric, she adds. Others still might suffer delusions in addition to their undiagnosed neuropathic illness. Even so, "It's not up to some primary care physician to conclude that a patient has a major psychiatric disorder."

The CDC is due to publish a long-delayed study on the condition and, if it proves Oaklander's theory correct, this would explain a great deal. Why, for example, Greg Smith's lesions stopped developing when he stopped scratching: because they were self-inflicted. Why I found fibres on my hand: because they are picked up from the environment. What's more, if morgellons is not actually a disease but a combination of symptoms that might have all sorts of different maladies as its source, this squares with something Smith said she's "constantly perplexed about when I find a treatment that helps one person, it doesn't help the next at all. Every patient is a whole new ball game."

I phone Paul and explain the itch-nerve theory.

"I can't see how that relates to the physical condition," he sighs. "I've got marks on my back that I can't even reach. I've not created those by scratching."

I ask how he has been. "Pretty crap, actually. Been forced out of my job. They said it's 'based on my engagement level', and that's down to the lack of energy I've got. I can't sign myself off sick or as having a degraded performance because morgellons is not a diagnosis. There's no legitimate reason for me not to be operating at full speed."

There's a silence.

"Another thing has been destroyed by this disease," he says finally. "And all because morgellons isn't supposed to exist."

Some names have been changed.

Source: The Guardian
<http://www.guardian.co.uk/lifeandstyle/2011/may/07/morgellons-mysterious-illness>

Part 2.

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