Is It Disease or Delusion? U.S. Takes on a Dilemma

By MICHAEL MASON

After an avalanche of panicked inquiries from patients across the country who claim to have been stricken with a mysterious skin disease, the federal Centers for Disease Control and Prevention is preparing to begin a full investigation.

The patients, clustered in California, Texas and Florida, describe symptoms that include sores that are slow to heal, a sensation of things crawling through their skin, joint pain and persistent fatigue.

Many say they believe they have Morgellons disease, a diagnosis that has received wide attention on the Internet but is viewed skeptically by some doctors, who suspect that it is psychosomatic in origin.

In its investigation, to be carried out in Southern California, the centers will conduct environmental tests as well as physical and psychological evaluations of people who say they are afflicted.

“If it’s a new bug or something, we’ll find it pretty quickly,” said Dan Rutz, a spokesman for the centers and a member of the task force planning the investigation.

“Our minds are open to all the possibilities,” he said.

Whatever its cause, Morgellons disease joins a growing list of symptom clusters that public health officials have been forced to examine closely in part because of the organizing power and unprecedented reach of the Internet.

Morgellons was brought to public attention by a woman in South Carolina, Mary Leitao, who in 2001 created a Web site describing the mysterious sores and bizarre threadlike extrusions that afflicted her young son. She said she had tried for years to find a medical explanation for his illness. Ultimately, she said, doctors accused her of staging it.

Ms. Leitao named the condition Morgellons after a 17th-century medical study she’d found that described French children with roughly the same symptoms.

After creating the Web site, she said, she was inundated with e-mail messages from people who said they also had the disease. More than 7,000 people claiming to have Morgellons have registered on the site.

Brandi Koch, 31, is one of them. Ms. Koch said her illness began three years ago, when her arms and legs started to swell. Doctors diagnosed an autoimmune disease, perhaps arthritis. A few months later, Ms. Koch’s back became spangled with lesions; doctors said it might be scleroderma.
A self-described “Type A personality,” Ms. Koch said she increasingly felt forgetful and detached. **Lyme disease**, the doctors decided.

“They then the horror really started,” Ms. Koch said. “I noticed there was some kind of matter coming out from my skin, not just from where I had sores.”

The substance, visible to others, was like large flecks of black pepper, said Ms. Koch, who worked out regularly and competed in 10K races before she fell ill.

After a dozen doctors failed to provide a diagnosis, Ms. Koch discovered Ms. Leitao’s Web site and realized that she had Morgellons disease.

“It is the most terrifying, disgusting, horrific thing I’ve ever had,” Ms. Koch said. “I don’t know how anyone could have it without feeling a little crazy.”

Ms. Leitao said that many of the people who visit her site have been told by doctors that their symptoms are delusional — the province of psychiatry rather than infectious disease. Several mothers, Ms. Leitao said, told her that they had lost custody of their children after doctors decided the youngsters’ symptoms were contrived. Earlier this year, a young man in Texas reportedly committed **suicide** after struggling with what his mother has described as Morgellons.

Doctors themselves are divided over whether Morgellons is a medical or a psychiatric illness. The patients are clearly suffering from something; it is just not clear what that something is.

“I think it’s a real disease,” said Dr. Rafael Stricker, a physician in San Francisco who sees many patients claiming to have Morgellons.

“Certainly there is an element of psychiatric distress here, but that’s because the patients are ill and nobody wants to listen to them,” he said.

Many patients also test positive for Lyme disease, Dr. Stricker has found; certain antibacterial and antiparasitic medications sometimes seem to alleviate the symptoms, he said.

But doctors said that after testing the skin extrusions, laboratories routinely dismiss them as plant or textile material.

“You send away the blood work and specimens, you don’t get anything back,” said Dr. Neelam Uppal, a physician in St. Petersburg, Fla., who treated Ms. Koch and has seen a dozen other patients with similar symptoms.

“I feel it’s a parasite, perhaps a fungus,” Dr. Uppal said. “You have to give patients the benefit of the doubt.”

Despite hints of a physical cause, most patients are eventually confronted with a psychiatric diagnosis. The symptoms bear a close resemblance those of delusional parasitosis, a disorder in which sufferers, often drug abusers, believe they are afflicted with hidden parasites and resist all evidence to the contrary.
Researchers have found that delusions like this can be passed from primary patients to secondary ones, usually susceptible family members or close associates. Psychiatrists call this phenomenon folie a deux.

In one remarkable case, a woman convinced her husband that neighbors were shooting at her with lasers. In another, an elderly woman convinced her live-in sister that they were both being attacked by bugs.

“Parasitosis is a classic form of shared delusion,” said Dr. Mary Seeman, an emeritus professor of psychiatry at the University of Toronto. “Skin disease is perfect for it. A person gets a rash or something, then the ‘disease’ spreads through any shared space in which there is close contact.”

But the Internet may have greatly altered the dynamics of folie a deux. In the connected, always-on world, separation is no longer so easy, and delusions may be shared and supported far beyond the confines of the home or workplace.

“Morgellons patients feel they’ve been jerked around without getting the care they need,” said Mr. Rutz of the disease control centers.

“Often they show up at the doctor’s office with all this stuff they’ve found online or in the media, and when they try to explain it to a skeptical physician, communication just breaks down,” he said.

While much has been made of the Internet as a medium for psychological support, experts have only begun to ponder its potential for spreading delusional thinking.

“When a person has something bothering him these days, the first thing he does is go online,” Dr. Seeman said. “You can get reinforcement of your ideas very quickly there.”

Those who believe they have this strange new illness have grown accustomed to questions about their mental health.

Ms. Koch, for example, is weary of medicine’s harsh judgments and has all but abandoned doctors’ offices. “If I thought they were really serious about doing the research, I could give them the show of a lifetime,” she said.

“I wish I were nuts,” she added. “That would be the best-case scenario in some ways. But I’m not.”