



Morgellons Disease Stumps Experts
CDC Launches Investigation of Rare Skin Problem
By Jeanie Lerche Davis
WebMD Health News
Reviewed by Louise Chang, MD

Jan. 17, 2008 -- A mysterious skin problem is erupting all over the country -- and it's caught the CDC's attention. It's been called Morgellons disease, and health officials don't know what to make of it.

More than 11,000 people in the U.S. and elsewhere have reported the same symptoms: itchy, severe skin sores with strange fibers "growing" out of them. There are creepy-crawly sensations, like insects crawling beneath their skin. Fatigue, difficulty concentrating, memory loss, and visual disturbances have also been reported.

The CDC is about to launch a study investigating this illness and has contracted with Kaiser Permanente of Northern California as its location.

In California, both the San Francisco Bay area and Los Angeles are considered "hot spots," with a large concentration of self-reported cases of the symptoms, reports Michele Pearson, MD, the CDC study's principal investigator.

Initially, Texas and Florida also had large numbers of "self-reports," says Pearson, but now they're coming from all 50 states as well as Canada, the United Kingdom, and Australia.

"Exactly what this means, we don't really know," Pearson tells WebMD. "We hope to look at this critically. Are these true clusters of illness or are there more cases because these are large population centers?"

Patients Are Desperate

"There's a lot of speculation about this," Pearson says. "We don't know if this is a new problem or newly recognized problem. We don't know if it's infectious. We don't have any good evidence that it's communicable. However, there are good reports of clustering within families and within households. We are going to look at true clustering in regions and in households."

What she does know, Pearson says, is that "patients are fairly desperate. They are suffering. Many have felt so alienated from the traditional care system that they are seeking some alternative therapies."

Many doctors are similarly frustrated, says Pearson. "They don't feel they have anything to offer patients. Patients feel they are fairly quickly dismissed as having a delusional disorder or psychiatric disorder as a primary cause for their symptoms. When that occurs, they tend to drop out of traditional care systems and look at alternative treatments."

"It's clear that this is a complex disorder and is likely due to multiple factors," she explains. "Some common conditions may be causing the symptoms--diabetes, thyroid conditions, autoimmune conditions. These can present with chronic ulcerative lesions, chronic itching. Those are some things we hope look for as part of our evaluation."

Kaiser Permanente was chosen for the study because of its electronic search system, Pearson says. "We can query their database for certain diagnoses and symptoms, complaints. We can try to identify people who came in with fibers, threads, and other symptoms. It's a good way to identify patients who are potentially eligible."

Case Study of Morgellons

Mary Leitao, a biologist in Pittsburgh, was spreading cream on her 2-year-old son's arm when she noticed something very unusual. "I saw this material, this fibrous material, come out of his skin. ... It was balls of fiber, like they were all bound together. When I applied the cream, they came out of his skin."

He soon began itching -- a lot -- and developed "pretty severe skin lesions," Leitao tells WebMD. "He would wake up with bloody bed sheets and was very, very uncomfortable. It was frightening."

Most frightening, and frustrating, was the dearth of information on this condition. "I'm a scientist. I did literature searches, and nothing could be found." But online she quickly met people with the same condition.

It was Leitao who called the condition "Morgellons" in 2002, naming it after a seemingly similar illness first described centuries ago. She then launched the Morgellons Research Foundation web site. It provides a registration service for people to report their symptoms.

Since 2002, up to 11,059 families have registered on her site, says Leitao. In November 2007, Leitao notified the CDC that 37% of those families had multiple family members with the symptoms.

Difficult Investigation

"It's going to be a difficult investigation," says Pearson. "We're trying to figure out this unexplained condition for which we don't have a blueprint. The symptoms are complex. We'll be looking at the range of symptoms and the extent to which it overlaps with other conditions."

Patients in the study will get comprehensive exams -- a general medical exam, dermatological exam, blood tests, chest X-rays, urine samples, and skin biopsies. "They also will get a mental health exam, so we can screen for common psychiatric disorders -- and for real evidence of cognitive deficits," Pearson says.

"It's clear that this is a complex disorder and is likely due to multiple factors," she says. "Some common conditions may be causing the symptoms -- diabetes, thyroid conditions, autoimmune conditions. These can present with chronic ulcerative lesions, chronic itching. Those are some things we hope look for as part of our evaluation."

As for Leitao's son, "he's much improved, although we're not sure why," she says. "We tried antibiotics, other medications. We're not exactly sure what helped." However, her older children have developed the skin symptoms as well, though not to the extent her youngest son had them.

"They have more fatigue, which is very, very typical for adults who develop this," says Leitao. "The fatigue can be pretty life-altering. Their fatigue has not improved, and it's a big concern to me."