

## INFECTION FOCUS:

# Morgellons

CDC to launch study on unexplained illness

The Centers for Disease Control and Prevention (CDC) in conjunction with Kaiser Permanente's Northern California Division of Research launched a study to learn about an unexplained skin condition known as Morgellons. Persons who suffer from this condition report a range of symptoms including non-healing skin lesions associated with the emergence of fibers or solid material from the skin, abnormal skin sensations (such as stinging and biting or pins and needles) and non-cutaneous symptoms such as difficulty concentrating and short-term memory loss. Researchers hope to learn more about who might be affected, what symptoms they experience, and factors that may contribute to their illness. "We earnestly want to learn more about this unexplained illness which impacts the lives of those who suffer from it," said Dr. Michele Pearson, principal investigator leading the study for CDC. "Those who suffer have questions, and we want to help them."

CDC will identify patients in Kaiser Permanente's Northern California Health Plan to enroll in the study. The Kaiser Permanente Division of Research was awarded a \$338,000 contract to assist CDC in this investigation because of the organization's location in a geographic area where self-reported cases are concentrated, the size of the patient population to draw from (Kaiser Permanente covers approximately 30 percent of the Northern California population), and its ability to systematically identify Kaiser Permanente patients who may have this unexplained illness.

"CDC is taking a multifaceted approach to this investigation with other external partners including the Armed Forces Pathology Institute," Dr. Pearson said. "We have a team of epidemiologists, laboratorians and pathologists to carry out the study," Dr. Pearson added. The primary goals of the investigation are to better describe the clinical and epidemiological features of this condition and to generate hypothesis about possible risk factors.

The investigation may take 12 months or longer to complete. Initially investigators will identify and recruit participants and collect detailed information on participants' symptoms and potential factors that may contribute to the condition. Later eligible participants will undergo detailed clinical evaluations, including a general medical examination, dermatologic examination, mental health examination, skin biopsies, and multiple blood tests.

Results of this investigation will most likely be published in CDC's weekly bulletin called the *Morbidity and Mortality Weekly Report* or a peer-reviewed scientific journal. A designated Web site and voice message line with prerecorded messages (404.718.1199) has been established and will provide updates about the investigation and new information as it becomes available. Interested persons are encouraged to visit the CDC's Unexplained Dermopathy/Morgellons Web site ([www.cdc.gov/unexplaineddermopathy](http://www.cdc.gov/unexplaineddermopathy)) to obtain current information about CDC activities related to this condition. †

## Morgellons

### General Information

Recently, the Centers for Disease Control and Prevention (CDC) has received an increased number of inquiries regarding an unexplained skin condition which some refer to as "Morgellons." Persons who suffer from this unexplained skin condition report a range of cutaneous (skin) symptoms including crawling, biting and stinging sensations; granules, threads, fibers, or black speck-like materials on or beneath the skin; and/or skin lesions (e.g., rashes or sores). In addition to skin manifestations, some sufferers also report fatigue, mental confusion, short term memory loss, joint pain and changes in vision.

The cause of this condition is unknown, and the medical community has insufficient information to determine whether persons who identify themselves as having this condition have a common cause for their symptoms or share common risk factors.

### CDC Investigation

The suffering that many people associate with this condition is best addressed by a careful, objective scientific analysis. Considering the complexity of this condition, we believe that a measured and thorough approach offers the best chance for finding useful answers. *continued on page 54*

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To learn more about this condition, CDC is conducting an epidemiologic investigation. CDC has awarded a contract to Kaiser Permanente's Northern California Division of Research to assist CDC in the investigation of this condition. The study is being designed and led by CDC.

The primary goals of the investigation are to help us learn more about who may be affected with this condition, the symptoms they experience, and to generate hypotheses about factors that may contribute to it. The investigation will involve: determining the clinical and epidemiologic features of this condition; assessing the histopathology of skin biopsies from affected patients; characterizing foreign material such as fibers or threads obtained from persons with the condition; describing the geographic distribution of this condition; and estimating rates of illness among the study population.

### **Frequently Asked Questions**

1. Does CDC have evidence that this is a new condition? We do not know the cause of this condition or whether this condition is new. CDC has received an increased number of inquires from persons who report similar symptoms; therefore, we are conducting an investigation to learn more about this unexplained dermopathy.
2. Does CDC have evidence that this condition is increasing? CDC has received an increased number of calls regarding this condition; however, this may represent an increase in the awareness of this condition rather than an actual increase in the number of persons with this condition.
3. Is this condition contagious? The factors associated with acquiring this condition are unknown. At this time, there is insufficient information to determine whether or not this condition is contagious.
4. Why did CDC select Kaiser Permanente Northern California as the partner for the investigation? This condition is thought to be rare; therefore, CDC sought a location and an organization that would likely have an adequate number of affected persons to be able to conduct a careful investigation. There are several factors that led CDC to select Kaiser Permanente Northern California as the partner in this investigation. First, Kaiser Permanente Northern California is located in a geographic area where self-reported cases of this condition are concentrated. Second, Kaiser Permanente has a membership that comprises a large proportion of the population in the Northern California area, thereby allowing estimation of rates of the condition in the population. Third, Kaiser Permanente has electronic health records that will allow a systematic method of identifying persons who may have this condition.
5. Who will be eligible to participate in the investigation? Participant selection will follow a set protocol, and not all persons who identify themselves as having signs or symptoms of this condition will be eligible to participate in the investigation. If you are identified as eligible to participate, you will be contacted by the study staff members. To be eligible, one must reside in the Northern California area, be at least 13 years old, have been a health plan member of Kaiser Permanente Northern California during July 2006 through December 2007, and have compatible signs and symptoms of the condition as described in the investigation protocol.
6. How long will the investigation take? The investigation will occur in phases with an estimated timeframe of 12 months or longer to complete the entire investigation, including obtaining results of blood tests and skin biopsies. During the first part of the study, the investigators will identify and recruit eligible study participants and collect detailed information on participants' symptoms and potential factors/ exposures that may contribute to the condition. In the second part of the study, eligible participants will undergo detailed clinical evaluations, including a general medical examination, a dermatology examination, a mental health examination, skin biopsies, and multiple blood tests.
7. May I send samples to the CDC laboratories for confirmation of this condition? CDC is not able to accept specimens or samples for testing, and we are not aware of any public health labs that are performing tests specifically related to this condition. Persons who believe they may suffer from this condition should contact a healthcare provider for evaluation and medical care.
8. Can you advise on the steps that I should take to report this condition? "Morgellons" is not a condition that is reportable. Persons who believe they may suffer from this condition should contact a healthcare provider for evaluation and medical care. CDC is not a clinical facility and does not provide clinical care or consultation to patients.
9. Does CDC plan to expand the investigation to other locations or include other persons who may be affected with this condition? The current investigation will be limited to Northern California and to persons who meet the study's eligibility criteria. Decisions regarding future studies will be determined based on the findings of this investigation.
10. If I have more questions about CDC's investigation, what should I do? Inquiries regarding this investigation can be sent to: e-mail [morgellonssyndrome@cdc.gov](mailto:morgellonssyndrome@cdc.gov) or phone 404.718.1199 (pre-recorded message with voicemail). At this time, we are not able to provide individual responses to each inquiry, but our public inquiry e-mail and phone line are checked regularly. Answers to frequently asked questions will be posted to CDC Web site [www.cdc.gov/unexplaineddermopathy](http://www.cdc.gov/unexplaineddermopathy), and this Web site will be updated with new information as it becomes available. †