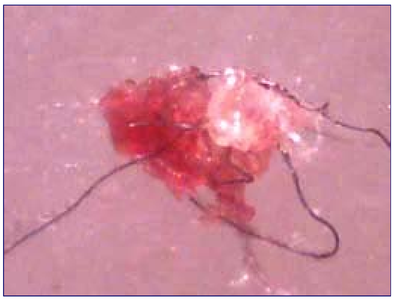
Morgellons Fiber Composition Still Unknown

> *"Morgellons fiber samples have been looked at in our collaboration with the Tulsa, Oklahoma, Police Department Forensics Laboratory. ... these Morgellons fibers don't match anything in their data base."*
> - Randy Wymore, Ph.D., Oklahoma State University



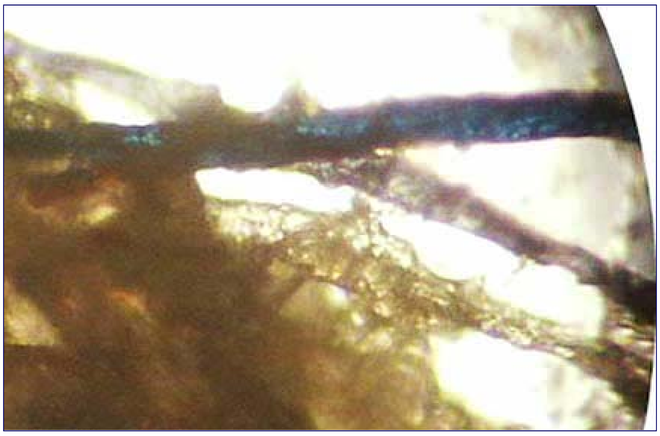
Unidentified microscopic fibers attached to excised skin lesion. Photomicrograph 250x courtesy Morgellons Research Foundation.

April 16, 2008 Tulsa, Oklahoma - The mystery has only had a name for about ten years. It's called Morgellons disease, or syndrome. On March 29, 2008, the Charles E. Holman Foundation organized a conference in Austin, Texas, about Morgellons and how to raise serious money for medical research.

Symptoms of Morgellons include itching, painful lesions that open up on the skin. Under a microscope, very small fibers in blue, red or translucent colors can be seen in the lesions under a magnifying glass and pulled out with tweezers.

Morgellons lesions typically contain microscopic fibers that sufferers say are an agony of painful itching.

Recently, I talked with one of the pioneers in Morgellons research. He is Randy Wymore, Ph.D., Director of the Center for Investigation of Morgellons Disease at Oklahoma State University and Assoc. Prof. of Pharmacology in OSU's Center for Health Sciences in Tulsa. I asked him if there has been any progress in finding out exactly what the composition of the red, blue and white fibers is?



Three Morgellons fibers in all three colors: clear on the bottom, red in the middle and blue on top. Photomicrograph courtesy Morgellons Research Foundation, OSU.

Interview:

Randy Wymore, Ph.D., Director,
Center for Investigation of Morgellons Disease,
Oklahoma State University. Image courtesy OSU.

Randy Wymore, Ph.D., Director of the Center for Investigation of Morgellons Disease at Oklahoma State University and Assoc. Prof. of Pharmacology in OSU's Center for Health Sciences, Tulsa, Oklahoma : "No, we don't have answers about the Morgellons fiber composition yet. Morgellons fiber samples have been looked at in our collaboration with the Tulsa, Oklahoma, Police Department Forensics Laboratory. They have analyzed a few more fibers (from Morgellons patients) and interestingly enough, they claim that a couple of these Morgellons fibers don't match anything in the data base. Does that happen very often?

First of all, I asked specifically that question the last time I was over there and I was told that whenever they get samples that they do FTIR spectroscopy and it always comes up with a match - except in the case of the Morgellons fibers. So, the technology works great. It's the Morgellons fiber samples that are the unusual things in this process.

One of the problems is that everyone who does this analysis work is just doing it out of the goodness of their heart or out of intellectual curiosity. We don't have any large funding that would allow many people to work on this full time. As a result, I am constantly trying to find experts in different fields, of which I am not, to try to move this forward.

WE ASSUME THAT POLICE DEPARTMENTS AND THEIR FORENSIC LABS ARE GOOD ENOUGH TO ANALYZE EVIDENCE TO STAND UP IN COURTS OF LAW. WHAT HAVE THE FORENSIC EXPERTS IN THE POLICE DEPARTMENT THAT HAVE LOOKED AT THE MORGELLONS AND NOT BEEN ABLE TO COME UP WITH A MATCH - WHAT HAVE THEY SAID ABOUT THAT?

They are completely blown away by it. In both cases, the two fiber experts at the Tulsa Police Department Forensics Lab, each of them has over twenty-five years of experience doing fiber and other analyses. Both of them participated in this, both visually and using spectroscopy. They are shocked that there could be something like this so far out of the ordinary.

They are familiar with Morgellons and the whole controversy of dermatologists saying, 'Well, this is impossible. This is nothing more than an internet hysteria and a subset of delusions of parasites.' The police lab analysts feeling as non-medical experts is that the very thing (fibers) that the patients are complaining about, the fibers don't match anything in the data base, so they can't simply be environmental contaminants. Therefore, there really must be some kind of new disease.

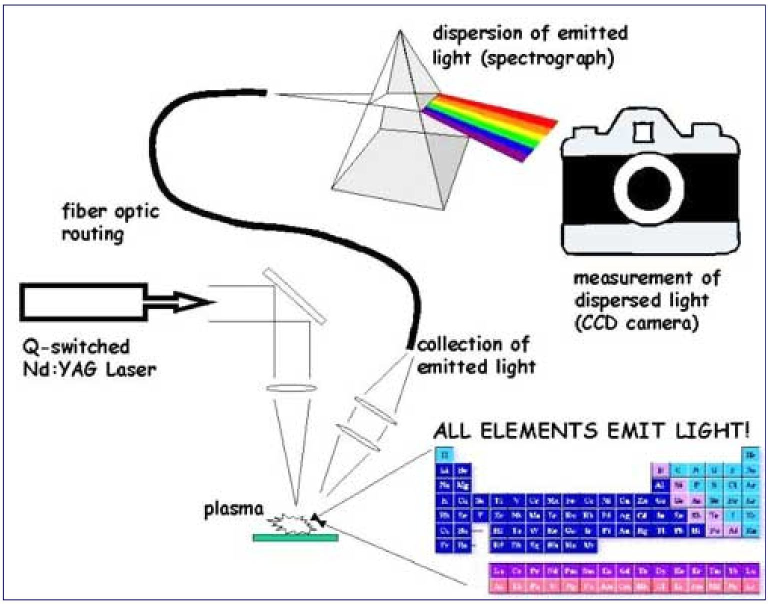
Something to understand about the police forensics lab - they analyzed the fibers in great detail. But what the analysts are trying to do is match to knowns in their data base. They are not equipped to take an unknown and sort through all the various peaks and troughs on the FTIR fingerprint, as it were, to try to figure out what the composition of the fibers are. That's where I need the academic or industrial chemists and material scientists to sort through this to try to figure out what the fibers are actually made of.

Laser-Induced Breakdown Spectroscopy (LIBS)

HAS ANYONE TRIED ENERGY DISPERSIVE SPECTROSCOPY (EDS) TO ANALYZE WHAT EXACTLY IS IN THE FIBERS?

It might sound odd, but there is a geologist I am working with who is going to do something similar to that - it's a type of laser ablation that they use on geological material to try to get elemental composition. The process works on a very tiny sample, which many of the Morgellons fibers are visible to the naked eye, but only if you have really good eyes. They are about the size of a child's eyelash. So, if you had that in a tweezers and held it up to the light and you have good eyes or glasses, you can see one, but they are tiny.

Basically, what they will do is hit a fiber with a high energy laser, which will vaporize the material and it will get sucked up into a little chamber where the spectroscopy is done on it.



Schematic of an LIBS system, courtesy U. S. Army Research Laboratory.

So, at the very least, we hope to have an elemental analysis done within the next couple of months. All I can say is that definitely, the Morgellons fibers that we have had analyzed - and not just the spectroscopy - but other processes of high temperature exposure to these fibers can take without giving off any volatile gases. Polyethylenes of all sorts - low, medium, high density - I have not found any applications where over 1,000 degrees Celsius all of the organic compounds have not been volatized away. That does not happen with our Morgellons fibers. They do not match anything.

Morgellons Fibers Don't Vaporize At Normal Pyrolysis Mass Spec Temperatures

It is not that the lab analysts haven't looked hard and used the correct data bases to research the fibers. It's that in all the data bases they used - and it's not just by one technique. It's not just the FTIR spectroscopy. They've also done mass spec called pyrolysis mass spec. What they do is heat the fibers in a vacuum chamber. Normally, if you had cotton or hair or nylon or rayon or whatever - if you put a little fragment of that in this device, they evacuate the air making a vacuum, heat it and then the various organic compounds that this substance is made of - as you get to the boiling point, those vaporize away, it's detected in the device, and then the data base of compounds is searched to see what it most likely is. The problem is if there is nothing vaporizing away, there is nothing to compare it to. That particular data base is somewhere around 90,000 different organic compounds.

> [Editor's Note: *Wikipedia* - “Pyrolysis is the chemical decomposition of organic materials by heating in the absence of oxygen or any other reagents, except possibly steam. It is used in chemical analysis to break down complex matter into simpler molecules for identification, for example by pyrolysis gas chromatography mass spectrometry.”]

With the Morgellons fibers, after they had gone through this process and the vacuum was released and the air let back into the chamber, the forensic scientists were able to reach in with their tweezers and still pick up the fiber. It was still a fiber after all this. It had not been reduced to ash. Now, the Morgellon fiber had blackened. It had changed its shape. It was being affected by the temperature, but not to the point of completely breaking down as normally would be the case. The particular pyrolysis mass spec the Tulsa police lab used, they had taken it to the upper range of their machine. I mean, they can't make it hotter.

THE FIBERS ARE STILL INTACT AND THAT'S PART OF THE PUZZLE. BUT WHO DO YOU GO TO FOR HIGHER TEMPERATURE?

A materials or analytical chemistry lab or some organic chemistry labs would be able to do that. Even for a starting point, if we can get the elemental analysis, or get the FTIR signatures analyzed by someone who can spend the time to sort through and say, 'Here's some double bonded carbons, here's a methyl group, here's a hydrogen and so on. That might give us some sense of what these things are made of.

IS THERE ANY REASON TO HAVE NOT GONE IMMEDIATELY TO A MATERIALS LAB AND SAID, 'HERE'S WHAT HAPPENED IN THE POLICE LAB. CAN YOU TAKE THE TEMPERATURE UP AND TELL US WHAT THIS IS?

Well, I have to find someone who is willing to do that just out of interest."

Centers for Disease Control and Prevention (CDC) Launches 2008 Morgellons Study

The following is a January 16, 2008, transcript of a phone conference call with medical doctors, reporters and CDC representatives to announce “CDC Launch Study on Unexplained Illness.”

> Moderator: Dave Daigle
> January 16, 2008
> 2:00 p.m. EST
>
> OPERATOR: Good afternoon and thank you all for holding. At this time your lines have been placed on listen-only until we open up for question-and-answers. Please be advised, today′s conference is being recorded. If you have any objections, you may disconnect at this time. I would now like to turn the conference over to Mr. Dave Daigle, please go ahead, sir.
>
> DAVE DAIGLE: Thank you, Laura, and welcome everyone. I′m Dave Daigle with CDC′s press office. Today, we are announcing that the Centers for Disease Control and Prevention in conjunction with Kaiser Permanente′s Northern California Division of Research is launching a study to learn more about an unexplained skin condition known as Morgellons. This is a briefing for the working media. And we certainly understand that there are a lot of folks out there with questions, but we′re going to limit questions today to the working media.
>
> Joining us today are Dr. Michele Pearson, who is the principal investigator for the CDC. And Dr. Joe Selby, who is the Director of the Kaiser Permanente′s Northern California Division of Research. Drs. Pearson and Selby will provide short opening statements before we move to your questions. We′d ask you to

minimize follow up questions until we can ensure everyone gets a shot at asking a question. And with that, I introduce Dr. Pearson.

DR. MICHELE PEARSON: Thank you, Dave and good afternoon. I'd like to begin by providing some background on this condition. Over the past year or so, the CDC has received an increased number of inquiries, regarding an unexplained condition which some refer to as Morgellons. Persons who suffer from this condition report a range of dermatologic symptoms, such as skin rashes and sores associated with abnormal skin sensations, such as crawling, biting and stinging sensations and the presence of thread, fibers, other foreign material on or beneath the skin. In addition to these skin manifestations, many sufferers also report fatigue, mental confusion, memory loss, joint pain and changes in vision.

To date, the cause of this condition is unknown, and there is insufficient information to determine whether persons who identify themselves as having this condition, have common cause for their symptoms or may share common risk factors.

What is clear, however, is that those who suffer from this condition, as well as their family members and physicians who provide care to them have questions, and we want to help them find meaningful answers.

To assist in learning about this condition, CDC is conducting an investigation in collaboration with Kaiser Permanente's Northern California Division of Research and the U.S. Armed Forces Institute of Pathology. The primary goals of this study are to learn more about who may be affected with this condition, the symptoms they experience and to look for clues about factors that might contribute to the condition. We believe that the suffering that many people associate with this condition is best addressed by a careful, objective, scientific analysis.

Our study will aim to better define the clinical and epidemiologic features of his condition. We also will assess the histopathology of this condition based on skin biopsies from effected persons. We will attempt to characterize any form materials (ph) such as fibers or threads obtained from persons who are enrolled in the study. Describe the geographic distribution of the condition in the northern California area. And generate estimates about how common this illness among the study population.

In the first part of this investigation, we will identify and recruit, persons who are eligible for the study and obtain detailed information on their symptoms, and possible factors that may predispose them to these symptoms. In the second part of the investigations, our participants will undergo detailed clinical evaluations which will include a general medical examination, a dermatologic examination, a mental health examination, skin biopsies and multiple blood tests. We certainly understand that these are- those who are effected by this condition are very anxious for answers. But we estimate that it could take 12 months or longer to complete this investigation.

Let me conclude by saying that this condition is complex, and it may be due to multiple factors. We are certain that this study will not provide answers to all of the questions. This may be one of many studies that will need to be done on this condition. Nevertheless, we believe this study should provide some useful insights and information, not only to the medical and scientific community, but most importantly to persons who suffer from this condition. Thank you.

DAVE DAIGLE: Thank you, Dr. Pearson. And now, the Director of Kaiser Permanente's Northern California Division of Research, Dr. Joe Selby.

DR. JOE SELBY: Thanks, Dave. And, thanks to all of you who have joined us today. I would like to say first, a few words about why Kaiser Permanente's Division of Research here in Northern California is delighted to be participating in this groundbreaking study.

We recognize that we, here, at Kaiser Permanente are uniquely positioned to assist the CDC with the study for several reasons. First, we serve a very large representative population of members in an area with one of the highest self-reported rates of this condition in the United States. Kaiser Permanente serves 3.4 million members in Northern California.

We have an experienced research unit that can effectively identify members who have this condition, recruit and survey those members who are interested in participating. And we have clinical research facilities in which the clinical exams Dr. Pearson described can be performed, specimens collected and transported to the CDC and to the Armed Force Institute of Pathology.

Our study will proceed in three stages, starting almost immediately. In the first stage, we will identify all members who may have seen a Kaiser Permanente physician with symptoms suggestive of this condition at any point during the 18 months between July 1, 2006 and December 31, 2007, and determine whether they meet eligibility criteria for this study.

In stage two, all eligible members will be invited to complete a comprehensive Web based or telephone survey conducted by the CDC that examines the duration and severity of a variety of symptoms, reported exposures, other possible precipitating factors, emulating factors, including treatments that may have been found to help. And in stage three, those with active symptoms will be invited to come to the division of research for an extensive clinical examination including collection of skin biopsies, blood and urine samples.

We recognize that many people in the United States and elsewhere are currently suffering with symptoms from the constellation that has been called Morgellons Syndrome. They and their clinicians, as well, are very frustrated by the absence of any clear evidence of whether this is a distinct condition, what might cause it and how it can be effectively treated. We hope that this first study provides a foundation that will begin to address these important questions. Thanks.

DAVE DAIGLE: Thank you, Dr. Selby. Laura, do we have a reporter queued up?

OPERATOR: Thank you. At this time, if you would like to ask a question, please press star followed by one on your touch-tone phone. To withdraw your request, you may press star two. Once again, star one with any questions. Our first question comes from Miriam Falco, CNN Medical News, please go ahead.

MIRIAM FALCO: Hi, thanks for taking the questions. Dr. Pearson, I missed the top of this, so I may be asking you something you all ready explained, but number one, are you—even on the press release, it says mystery disease. And from what was just described by Dr. Selby it still seems is this a disease or not? Does the CDC consider this to be a real disease?

And then number two, this is going to be done in Northern California, but are you also consulting researchers in other states who have been working on this and researching this for quite some time now?

DR. MICHELE PEARSON: First of all, what is very clearly to us is that there are a number of persons who are suffering the condition and the symptoms that we described. Part of the reason, in a large part we're conducting this investigation is because we don't know what it is and this is really an unexplained condition. So we're hoping to learn a lot about, not only the constellation of symptoms, but the impact of this condition on those who are affected as well as things that might be causing and contributing to it.

So, we are really at the beginning, I think, of a learning curve of what this condition is, and all of this potential manifestations. In terms of our work and the formative work that's been done around designing this investigation, we have assembled here within the agency, really a multi-disciplinary group of experts representing various disciplines, chronic disease, environmental health, infectious diseases pathology. And we've also consulted with external experts including pathologists and representatives from the American Academy of Dermatology.

We've also spoken with many members of the stakeholder organizations and those who are effected with the condition.

DAVE DAIGLE: Thank you. Laura, do you have another question?

OPERATOR: Thank you. Our next question is from Stuart Boslow, with KTVT CBS.

STUART BOSLOW: Hi, doctors., thanks for taking our questions. My first question is, what type of selection process will you go through in identifying those who are not part of the Kaiser program?

DR. MICHELE PEARSON: This investigation is really going to be confined to persons who are members of the Northern California health plan.

DAVE DAIGLE: Dr. Selby, did you want to add to that?

DR. JOE SELBY: Just to confirm it, and to clarify that because one of our goals is to determine the rate at which this condition is occurring, we need to know not only how many cases there are but what is the size of the population that these cases are coming from? So we will not be able to see all cases occurring in the United States or even all cases occurring in Northern California. We will see the cases that come from the population defined by membership in Kaiser Permanente.

DAVE DAIGLE: Thank you. And thank you Stuart. Laura, do we have another one?

OPERATOR: Thank you. Our next question comes from Rob Forman with the CBS Early Show.

ROB FORMAN: Yes, a question, please for both doctors. This has been a mystery for some length of time. What was the impetus for, for lack of a better word, finally saying, "Today we are moving forward." And, also as I look at the map from the Morgellons Research Foundation, I see certain geographical patterns, what might they suggest to you at this early stage?

DR. MICHELE PEARSON: Why don't I take that, Dr. Selby. It's certainly, this investigation has, I think, moved slower than any of us would have liked. We are aware that many patients have suffered from this condition. And, I can tell you that here at CDC, we have really been seeing an increasing number of these reports over the last year or so. And over the last year or so, we really have been diligently working to plan a systematic and rigorous scientific investigation to look at this more critically.

You're correct that based on the self supported information that is on the Morgellons Research Foundation Web site would suggest that there is, for lack of a better term certain geographic hotspots. And part of our reasons for collaborating with Kaiser Permanente in Northern California is because they are located in one such area. And their geographic location, combined with their research resources and experience, their rich databases for systematically identifying patients, make them really one of the reasons that-main reasons we chose them to work with.

DAVE DAIGLE: Thank you, Rob. Laura, do we have another one?

OPERATOR: Thank you. Our next question comes from Liz Szabo, USA Today.

LIZ SZABO: Hi. I was wondering if you could tell me where these cases are concentrated. Are you seeing this around the world, areas of the world? Is it just the United States? And if you could tell me how many reports you've gotten at the CDC.

DR. MICHELE PEARSON: Well, let me just begin by saying that there is no systematic surveillance for this condition at this point. Much of what we know about this condition has been based on self reports, and is based on information that has been collected through a registry that's been established by the Morgellons Research Foundation. That registry would suggest that this is not a condition that is limited to the United States.

They have, at least, had patients report that they are suffering from these symptoms in several countries, including Canada, several European countries, and Australia. I'm sorry, what was the other part of your question, I think that was your- so it does not appear to be limited to the United States based on the information we currently have. But, again, there's not been any systematic collection of information about this condition.

DAVE DAIGE: Thank you, Liz. Laura, next question, please.

OPERATOR: Thank you. Our next question comes from Helen Branswell, The Canadian Press.

HELEN BRANSWELL: Hi, thanks very much. If I could follow up on and this is a question for a little bit, are there any reports from cases coming from developing countries, or sort of mid income countries. You mentioned

Canada. I know we've had people report here, and Europe and Australia, but I'm wondering if sort of other socioeconomic countries might fall in. And I'm also wondering if you could clarify something about how you are going to be enrolling people.

I think Dr. Selby talked about people who had already presented for care between July 1, 2006 and December 31, 2007, dose that mean you're not going to be recruiting people now? That if people haven't already sought care for this in that treatment group, they won't be included in the study?

DR. MICHELE PEARSON: Well, I'll address the question about developing countries, and I'll let Dr. Selby answer the questions related to recruitment. We don't know, and I'm not aware of any reports from developing countries or lesser developed countries. Dr. Selby.

DR. JOE SELBY: And I'll answer the part about identifying cases. Yes, it's true. We are estimating what's called a period prevalence rate. So, what is the prevalence during a fixed period of time. And that fixed period of time is purposely so that we can get the rates calculated in a timely way and get people examined, the past 18 months. That coincides with some data capacity that we are not enabled to use here.

But the importance—the important aspect of this is that we need a systematic approach, an approach that we can write down and define and tell the world, this is how we identified patients. It would not do, for example, to put an ad in the paper and say everybody who thinks they may have Morgellons Syndrome, please call. We would then not have a systematic sample. And there's no reason to think that if you did the same thing in Bismarck, North Dakota, I'll take a chance, that you'd get the same kind of response. So that would not be a useful read. So this is period prevalence rate based on a systematic approach to the data that Kaiser Permanente has at hand.

DAVE DAIGLE: Thank you, Helen. Next question, please Laura.

OPERATOR: Thank you. Our next question comes from Jia-Rui Chong, with the Los Angeles Times.

JIA-RUI CHONG: Hi. I was hoping two things. One that you could answer the previous question about how many reports you've actually received, that there are numbers on that. And, then, I had another question hoping that maybe you could straighten out some of the timelines for me. When was it that, I guess, patients or groups started requesting this? And then, what are the actual steps that the CDC took? Because I feel like there were rumblings about starting a study in 2006, and then maybe a couple of months ago, so I was hoping to clarify that.

DR. MICHELE PEARSON: OK. In terms of, as I said, this is not a condition for which there is an established surveillance system. So what I can tell you about what we have received at CDC are really inquiries related to these conditions, this condition. And essentially over the last year or so we've received about 1200 inquiries related to this condition. What that translates to in terms of actual reports of patients is a little bit difficult to decipher.

The Morgellons Research Foundation, for example, would suggest that they have in their registry some 10,000 families that have reported—self reported that they have this condition. And, importantly, one of the reasons that we are doing this fairly systematic investigation is really to try to get a better handle on quantifying how common this condition is in a population.

In terms of the timeline, one of the first things that the CDC did was establish really a cross agency task force in 2006 to really serve as kind of an advisory brain trust related to this investigation. And as I've said previously, this is a cross agency, multi disciplinary group to advise on sculpting a scientific investigation and protocol related to this investigation.

As I said, we realized and we all would like to have had this move faster. But what we've been doing over the last year or so is really designing a very careful rigorous scientific protocol. And much work has been going on prior to this announcement. And what I can say now is that we are ready to start, and patient recruitment will begin immediately.

DAVE DAIGLE: Thank you. Next question, please, Laura.

OPERATOR: Thank you. Our next question is from Will Dunham with

Reuters.

WILL DUNHAM: Hi, this is Will Dunham in the Reuters Washington Bureau. Dr. Pearson, I want to follow up on, I think, the first question that you were asked. Are you now not prepared to say that you believe that this is a real medical condition?

DR. MICHELE PEARSON: What I can tell you is real is the suffering that these patients are experiencing. I cannot characterize this as a syndrome, as disease. I can tell you it's an unexplained illness. That clearly, the suffering that these patients are experiencing is real. I've actually, as part of my preparation for taking on this scientific lead have actually seen not only as a scientist, but as a physician, a patient up close and personal, and I thought that was very important for me to do, as part of my preparation for this. I had read about it. I had had heard about it. And I talked to numerous patients over the phone, but I've actually had the opportunity to meet one of these patients first hand.

And what I can tell you is the suffering and the impact of this condition on their lives, whether you want to label it a disease or condition and I don't—I'm not so concerned with the label but what they're experiencing in terms of the suffering is real. And, I think, it's important and this is why the agency has decided to look into this in much more depth.

DAVE DAIGLE: Thank you, Will. Next question, please, Laura.

OPERATOR: Thank you. Our next question comes from Maryn McKenna CIDRAP News.

MARYN MCKENNA: Thanks so much for doing this. Dr. Pearson, you and Dr. Selby both said that you're ready to get started right away. So, does that mean that you have a case definition? And if do, could you explain for us, what, qualifies someone to be considered, someone that's suffering from this unexplained condition?

DR. MICHELE PEARSON: Yes, we have a working case definition. And what I can tell you that is also something during the course of this investigation, we hope to be able to refine and learn more about. To be eligible for the study, in addition to having been a member of Northern California Kaiser Permanente, the patients will have to have experienced some of the features that I told you are characteristics of this condition, which is having threads or fibers or foreign material coming from their skin either in association with soars and ulcers or abnormal skin sensation, such as pins and needle sensations, crawling sensations. And that is essentially the working case definition that we will be using for this investigation.

DAVE DAIGLE: Dr. Selby, did you want to add anything?

DR. JOE SELBY: No, she got it exactly right. Just to reemphasize the unique characteristic of the condition to date and of the case definition is the presence of those various types of foreign material.

DAVE DAIGLE: Thank you. And thank you Maryn, next question, please, Laura.

OPERATOR: Thank you. Our next question comes from Mike Stobbe with the Associated Press.

MIKE STOBBE: Hi, thanks for taking the question. Dr. Selby, are all of the patients going to go to the same place, facility? And then, what city is it for the clinical evaluation? Also, is there a follow up study in the works and can you tell us what that will be and when that's going to happen?

DR. JOE SELBY: OK. The first question first. The clinical examinations will be done in Oakland, California and the budget includes money to travel patients from the Northern California region at a certain extent to it that will require some travel and some overnight stays, and we budgeted for that. We expect some people will probably come from fairly far away.

And in terms of a follow-up study that's really more a question for Dr. Pearson. I'm not aware of another one at this time, although, as Dr. Pearson has already said, it seems highly unlikely that this would be the last study.

DR. MICHELE PEARSON: Yes, I'll just say that we really are taking a very methodical and step wide approach on this. And in many ways, we're sort of taking two steps back and starting with the basics. There are some very fundamental questions about this condition that we don't know. For example, we don't know if this primarily affects men or women. We don't know if it primarily affects the young or the old. So there are some very important basic questions that, I think, will help us better determine who's affected by this condition. To define the range of symptomology associated with this condition. And really hopefully give us some real good clues about where to look further.

DAVE DAIGLE: Thank you. Thank you, Mike. And Laura, next question, please.

OPERATOR: Thank you. Our next question comes from David Templeton, Pittsburgh Post Gazette. ‘

DAVID TEMPLETON: Yes, thanks for taking the question. The lady who started the foundation who early named it comes from the Pittsburgh area. And by all accounts she went through quite a bit of an ordeal to even get this to this stage. And I'm just wondering if you have this kind of fibrous situation with your skin, and these other symptoms, why would the medical community be so reluctant to say, I mean they were calling it psychosomatic and there was this psychiatric problem and all of that. When you see such symptoms, why has it been so long to recognize this as a potential problem that needed to be investigated?

DR. MICHELE PEARSON: I think the—I don't pretend to speak for all of the medical community, but as both a scientist and a physician, what I can say is, I think, that many of the providers who have seen these patients have been as challenged as the patients who are seeking care themselves. There is not textbook definition on this condition. There are many hypotheses about what might be causing and contributing it. And so it's been a very frustrating journey, not only for the patients, but also for the providers who provide care to them.

And, I don't think it's unique to this condition. I think this is the case for any unexplained illness where there really is limited scientific information about what it is and how best to approach it.

DAVE DAIGLE: Thank you. Laura, next question, please.

OPERATOR: Thank you. Our next question comes from Barbara Feder, San Jose Mercury News.

BARBARA FEDER: Hi, there. Just a question for Dr. Selby, you had mentioned earlier that there had been a number of reports within Kaiser, or that this was the largest group within the Kaiser system, perhaps in the northern California division. Can you clarify why you think you have a significant population within Kaiser Northern California? And also, you know, what kinds of numbers you might be looking at?

DR. JOE SELBY: What I said was that, Kaiser Permanent in northern California is a very large organization covering 3.4 million people in an area that based on reports that the CDC receives, and based on information published on the Morgellons Research Foundation Web site, that tell us that northern California is a very high frequency area for reports of this condition. So all I meant to say was that we're very large. We're representative of the population that lives in this area. We amount to about 30 percent of this population. And so we're well—and we have the ability to find the members, our members how have the symptoms of the conditions. So, I just meant to say we're well positioned.

I didn't mean to say that we had information at hand that said that the occurrence of this condition in Kaiser member was particularly high, and we will be finding that out as part of this study. And now I'm sorry, I've forgotten the second part of the second question.

BARBARA FEDER: Any sense of how many people you might…

DR. JOE SELBY: No, we really don't. I was just looking at the same map that a previous reporter mentioned that's on the Morgellons Research Foundation Web site, the number of cases. And, you know, if you want to be – I mean you can't do anything other than be—make a crude estimate from that, but a crude estimate would fall somewhere between 150 to 500 cases, I think, under varying circumstances. So, that's the broad ballpark that I believe we're operating in, but even that could be—even there I could be wrong.

BARBARA FEDER: And a follow up question. What size of a sample is appropriate for your study? I mean would you get to the point where if you felt like you did not have enough patients in your 18 month sample, that you would open it up? Or try to recruit patients by some other means?

DR. JOE SELBY: No. We will do—we're not going to sample. We're going to take everybody. And, so in a technical sense, it isn't a sample. We're quite confident it will be big enough for these- this is a descriptive study, so there are not pet hypothesis here to be tested. We are collecting data across a whole range of possible explanations. And for this, even that range, anywhere in that range that I mentioned would be reasonable. We would consider that reasonable for this first study. So, no, we do not anticipate any circumstances under which we'd have to go outside this membership. We will do the study here and we will report what we find.

DAVE DAIGLE: Thank you. Next question, please, Laura.

OPERATOR: Thank you. Our next question is from Larry Burns with KENS TV.

DEBRA NAPP: It's actually Debra Napp with Kens TV. And my question is, you talked about the hotspots. Is South Texas one of the hotspots for this condition?

DR. MICHELE PEARSON: I don't actually have the Morgellons map in front of me, but Texas—of the states within the United States, California, Texas, and Florida seem to be the areas where most of the self reported cases have originated.

DAVE DAIGLE: Thank you. And Laura, we have time for two more questions.

OPERATOR: Thank you. Our next question comes from Darla Fletcher, KCBS. Ms. Fletcher, your line is open, please check your mute feature or lift your hand set.

STACY BUTLER: Hi, it's Stacy Butler from KCBS. Let's face it, this is a creepy sounding disease. There's a lot of people out there that are concerned about this, what is your message today to a worried public?

DR. MICHELE PEARSON: Our message is simply that we are aware that several people are suffering from this condition. We don't, at this point, have any evidence that suggests that this is a communicable illness. And, that we are launching a systematic and rigorous investigation to learn more about it.

DAVE DAIGLE: Thank you. And last question, please, Laura.

OPERATOR: Thank you. Our final question comes from Margaret Burbank, CBS News.

MARGARET BURBANK: Hi, I'm actually from ABC. But most of my questions are answered. I guess, my only question is in the press release, it says that there's $338,000 that Kaiser is going to have. Is that the total amount of funding you have? And if so, if you're going to be taking everybody who comes to you, how feasible is it that you're going to be able to do a thorough study on all of them and possibly even take samples from them and everything you need to get a good view of what's going on?

DR. JOE SELBY: Well, we worked through the budget under those sample sized estimates that I mentioned and that's the figure that we came up with and that we signed a contract with CDC to conduct. Now, I should say, and Dr. Pearson can add to this, that not all of the cost of the study, by a long shot, are included in the money that came to Kaiser. So there's additional money being spent on this study by the CDC at the CDC, at the Armed Forces Institute of Pathology and probably elsewhere, that pay for some of these sophisticated analysis, the skin biopsies and some of the analysis of the foreign material, for example. So that may help to explain why we're able to do it.

DR. MICHELE PEARSON: Dr. Selby is correct. The 338,000 is a portion of monies that CDC had available in fiscal year 2007 to address this condition. In total, we have $545,000. And in terms of the question about whether this is enough to take everybody, I think it's important and I want to reiterate, this investigation is going to be confined to the members of the Kaiser Permanente Northern California health plan. This is not everybody in the United States or even everybody in the state of California.

We believe that this is—that based on our best estimates, a reasonable approach, and a good place to star, and a good start.

DAVE DAIGLE: Thank you, Dr. Pearson and thank you Dr. Selby. I want to thank also all of the reporters that took the time to join us today, and you as well, Laura.

END

More Information:

For further information about Morgellons syndrome, please see related Earthfiles reports below in the **Earthfiles Archives**:

• 06/25/2006 — Morgellons Disease: E-mail from CDC and Viewers/Listeners
• 06/23/2006 — Morgellons Agony of Skin Lesions and "Brain Fog"
• 06/03/2006 — Part 2: Bizarre Morgellons Disease: Letters From Viewers
• 06/01/2006 — Part 1: Bizarre Morgellons Disease: A Nurse Describes Her Own Symptoms

---

Websites:

Oklahoma State University: http://www.healthsciences.okstate.edu/morgellons/

Charles E. Holman Foundation: http://www.thenmo.org/

Centers for Disease Control and Prevention (CDC):
http://www.cdc.gov/od/oc/media/transcripts/2008/t080116.htm

Morgellons Hope: http://www.morgellonshope.com/content/view/254/215

Credits