



Effective Health Care

Link Between Morgellons and Lyme Disease Nomination Summary Document

Results of Topic Selection Process

The topic, *Link Between Morgellons and Lyme Disease*, focuses on two painful and potentially debilitating conditions that may be challenging to diagnose and manage. The nomination did not focus on a healthcare intervention and therefore could not be further assessed and considered by the Effective Health Care Program. No further activity will be undertaken on this topic. We encourage the nominator to continue to partner with their healthcare providers for the support and management of these conditions.

Nomination

Topic Number: 0497

Received On: 09/25/2012

Topic Name: Link Between Morgellons and Lyme Disease

Nominator: Patient

Nomination Summary: The nominator is interested in whether or not Morgellons can be linked to Lyme disease. Additionally, the nominator would like the causes and characteristics of Morgellons investigated. The relevant population for Morgellons and Lyme disease includes adults and children. This topic is important because it can be debilitating for those who present with symptoms, and there is significant financial burden. The nominator hopes that an AHRQ systematic review will identify knowledge gaps and inform research priorities for the Morgellons and Lyme disease population.

Key Questions from Nomination:

Key Question 1: Is there a link between Morgellons Disease/Syndrome and Lyme disease?

Key Question 2: What is the origin of the fibers embedded skin of an individual with Morgellons Disease/Syndrome?

Key Question 3: Can Morgellons Disease/Syndrome mimic hair follicles that are difficult to remove?

Key Question 4: Why does Morgellons cause Attention Deficit Disorder, Bipolar or Obsessive-Compulsive disorders?

Policy and/or Clinical Context from the Nomination: The nominator states that attention needs to be drawn to Morgellons for prompt recognition and diagnosis of the condition, funding of research, and coverage of related medical expenses.

Original Nomination

Topic Suggestion Description

Date submitted: 09/25/2012

Briefly describe a specific question, or set of related questions, about a health care test or treatment that this program should consider.

Can Morgellons Disease/Syndrome be linked to Lyme disease? Where do the fibers come from that is embedded in a persons' skin? Can this disease mimic the DNA of hair follicles that becomes very hard to remove from the given area? Why does Morgellons cause Attention Deficit, Bipolar or Obsessive-Compulsive disorders?

Importance

Describe why this topic is important.

This topic is important to me because I believe I have Morgellons. I seem to have these things in my throat. I choke a lot when I eat certain foods. I'm depressed. I keep my head down to the ground because I don't like people looking at my lower face because it's disfigured. Sometimes I just want to die; I can't because I have children and grandchildren. I spend hours pulling hairs and fibers out of my skin. The hair and fibers keep growing under my skin. Then I feel like the hairs and fibers and sticking me like a needle. I'm holding on because I view life as being special. Maybe I can help someone somewhere.

Potential Impact

How will an answer to your research question be used or help inform decisions for you or your group?

I will know if I have to keep on trying to find a cure on my own. I can't afford some products that seem to work. I get samples and my skin starts to clear-up somewhat. I don't have enough product, when the sample is gone, my skin condition comes right back. I believe that the inside of my body needs to be treated and also on the outside at the same time.

Technical Experts and Stakeholders

Are there health care-focused, disease-focused, or patient-focused organizations or technical experts that you see as being relevant to this issue? Who do you think we should contact as we consider your nomination? This information will not influence the progress of your suggestion through the selection process, but it may be helpful to those considering your suggestion for further development.

Oklahoma State University Center for Health Services OSU-CHS Center for the Investigation of Morgellons Disease
Randy S. Wymore, Ph.D.

Nominator Information

Other Information About You: (optional)

Please choose a description that best describes your role or perspective: (you may select more than one category if appropriate)

Patient

Please tell us how you heard about the Effective Health Care Program

If I remember right, I believe it was through a database from my library class. Students had to do a medical research as our assignment and I chose Morgellons. That's how I found the research web site.

May we contact you if we have questions about your nomination?

Yes