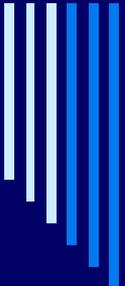


Morgellons Disease: Our Current Understanding

Dr. Ginger Savely

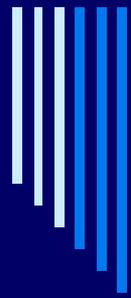
TBD Medical Associates, Washington, DC, USA





What is Morgellons Disease?

- A skin disease of unknown pathology, still under investigation
 - Characterized by sensations of crawling, biting and stinging, disfiguring lesions and unusual fibers coming out of the skin
 - Usually quickly dismissed by physicians as DOP (Delusions of Parasitosis) with skin lesions characterized as self-mutilatory
-



Primary Symptoms of Morgellons Disease

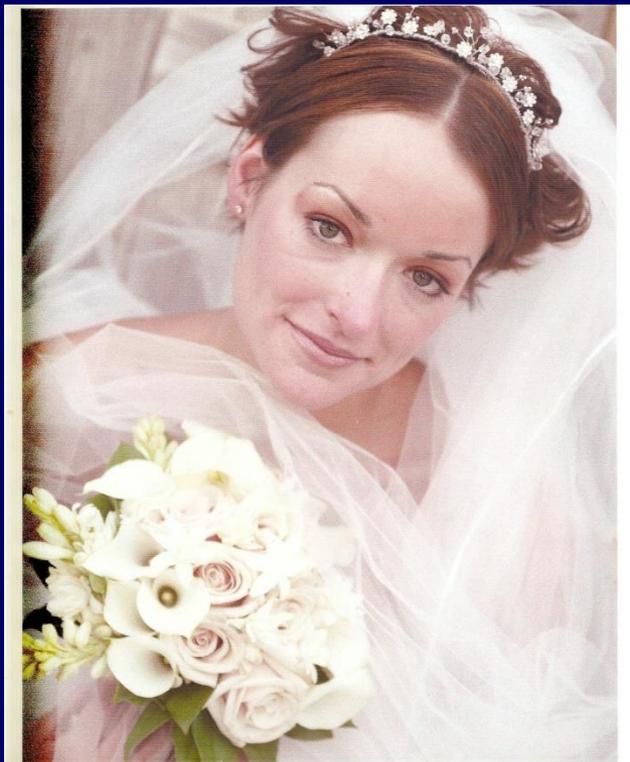
- Crawling and biting sensations under the skin
 - Spontaneously—appearing, slow-healing lesions
 - Fine, thread like fibers coming out of the skin
 - Intense itching
 - Painful sensations of something trying to penetrate the skin from the inside out
 - Slimy or gelatinous exudates
 - Black specs on skin
 - Hair loss and change of texture of hair
-



Morgellons Disease is NOT Delusional

- There is very much evidence to the contrary
 - Today we will discuss what we do know so far
 - Relevance for this conference: etiology appears to be vector borne and highly associated with spirochetes, particularly Lyme disease
-

Before.....and after.





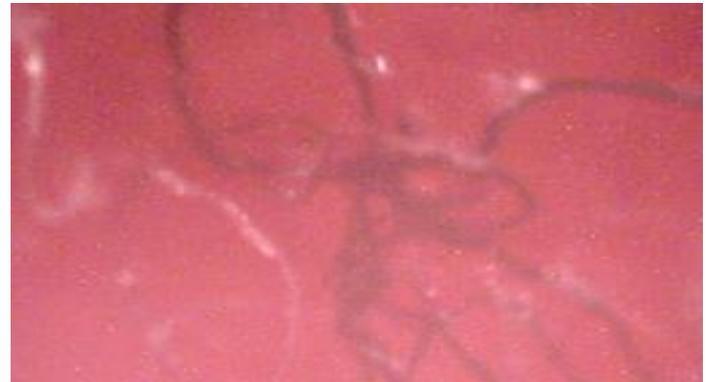


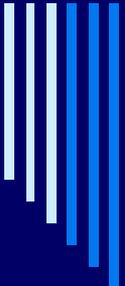
A Photo Sequence..



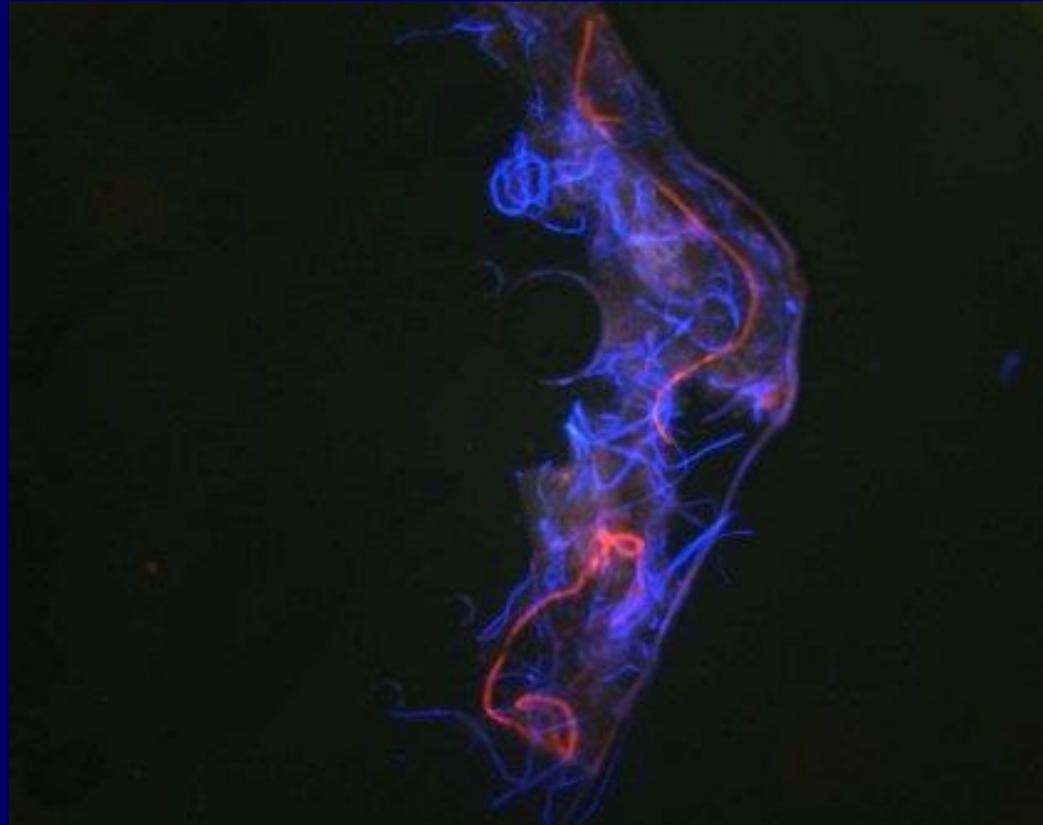
Continuing to focus in.....

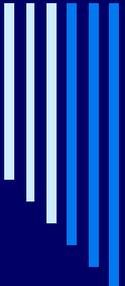
3 at 60X, 1 at 200X





Autofluorescence of fibers from skin lesion of lip of 3 year old male





This is seen at 200x on a patient's arm just under the outer layer of skin. This is not at all visible with the naked eye!



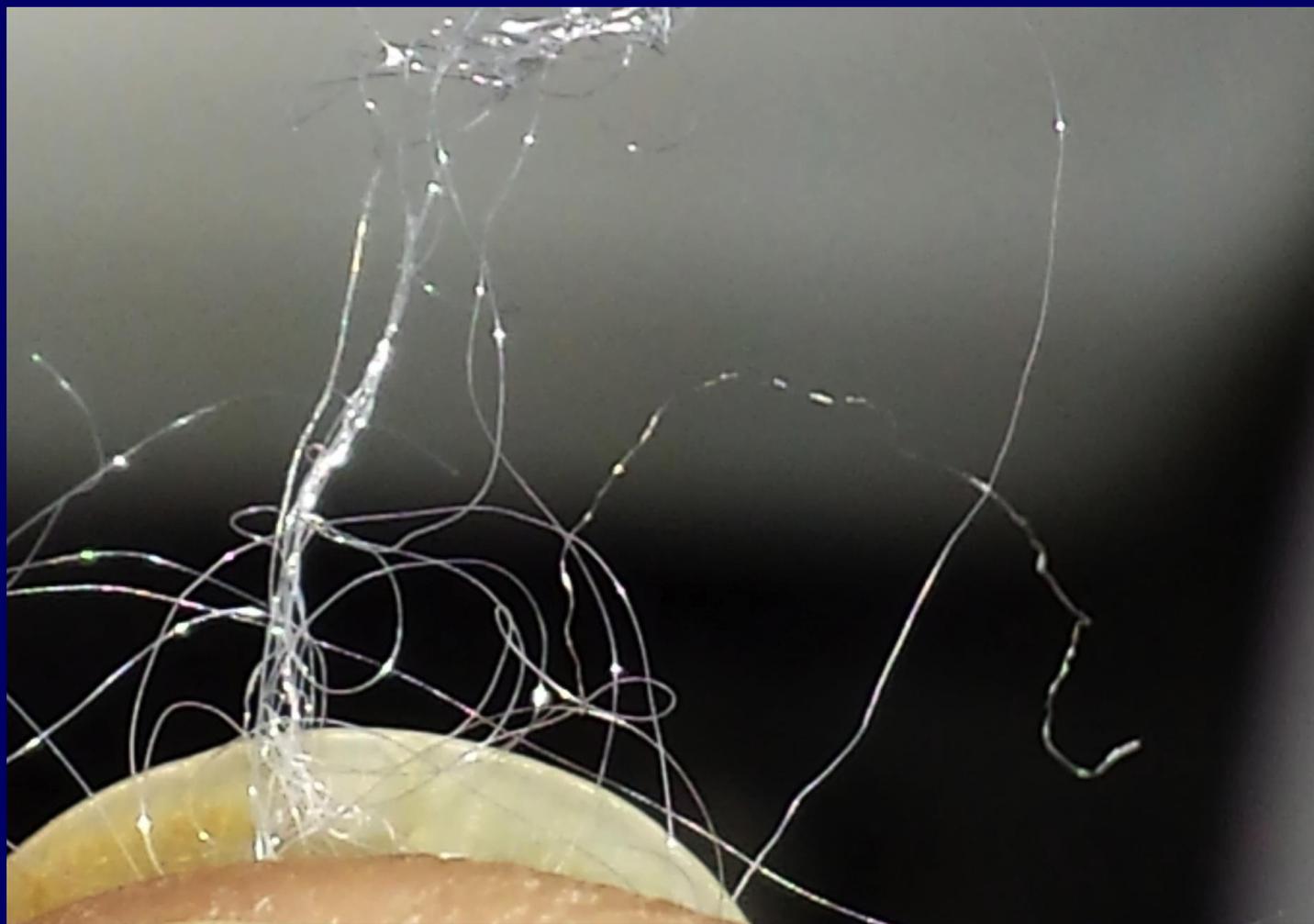
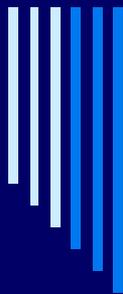




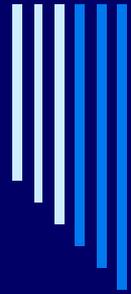






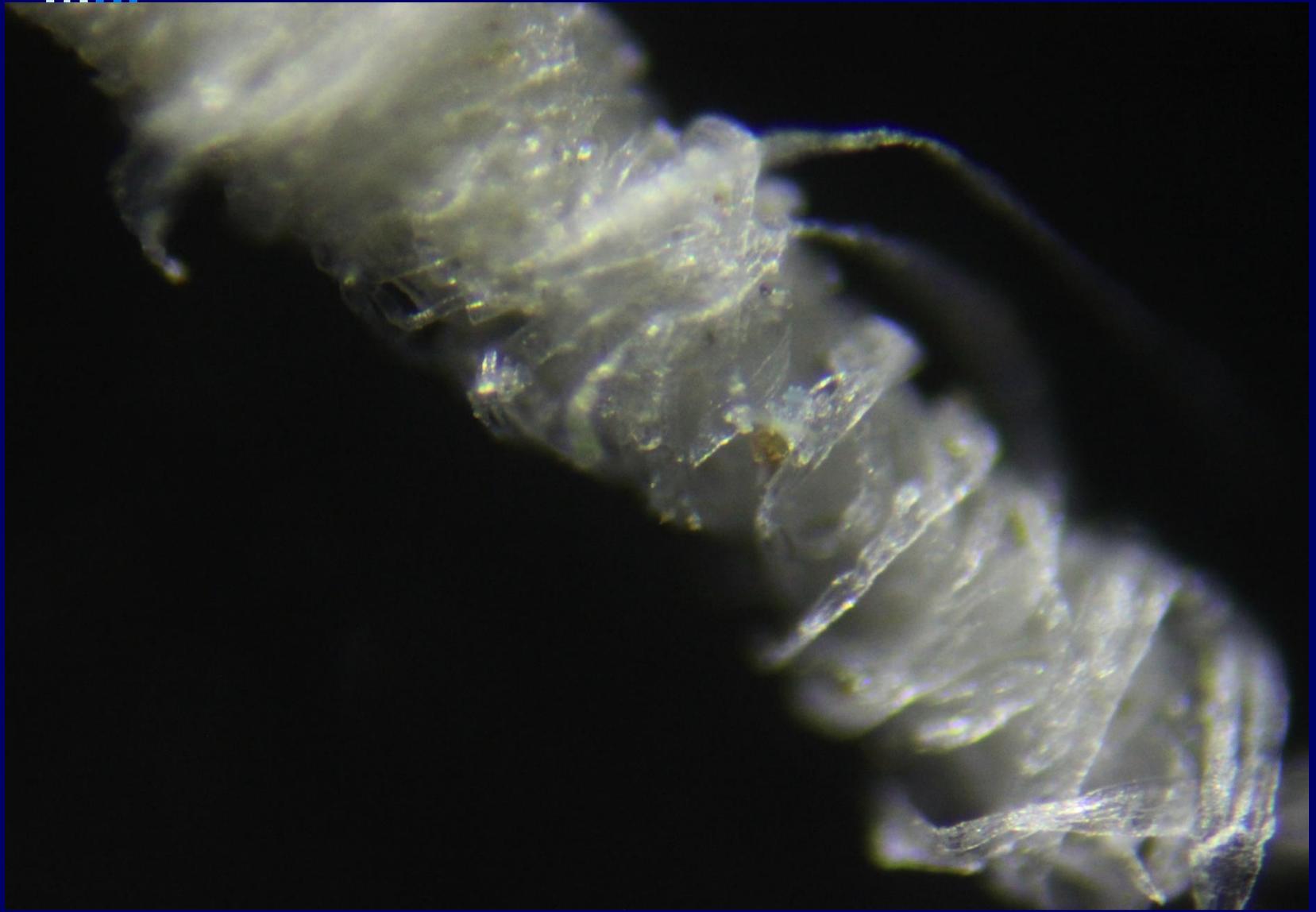




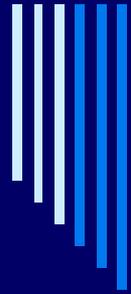


Patients Complain of Hair Feeling Coarse

- ❑ Filaments wrap themselves tightly around the hairs on patients' scalps
- ❑ This can only be seen with at least 400x magnification
- ❑ Makes hair feel coarse and also makes hair brittle and fall out
- ❑ Hair loss is common and some become partially or completely bald.

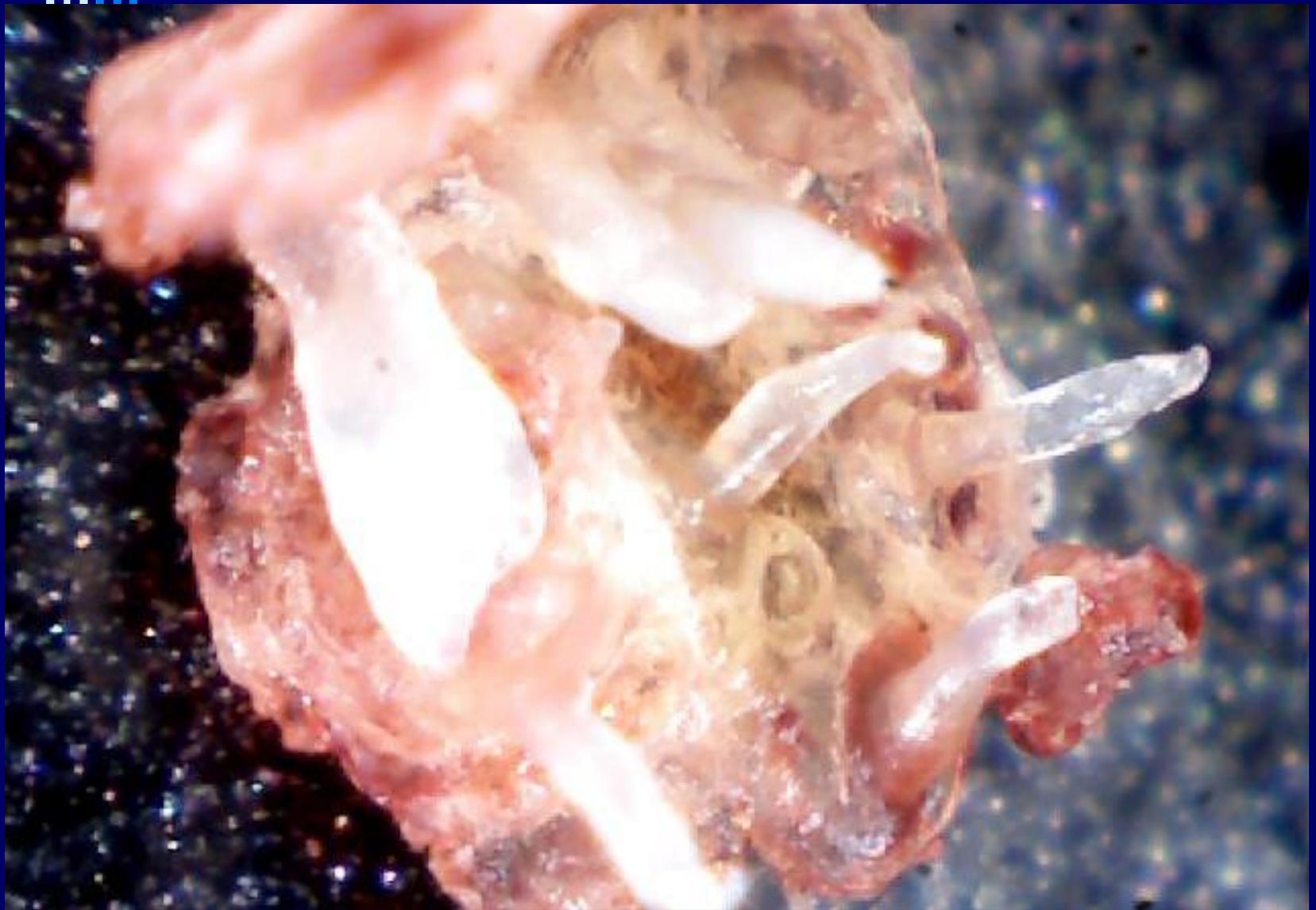




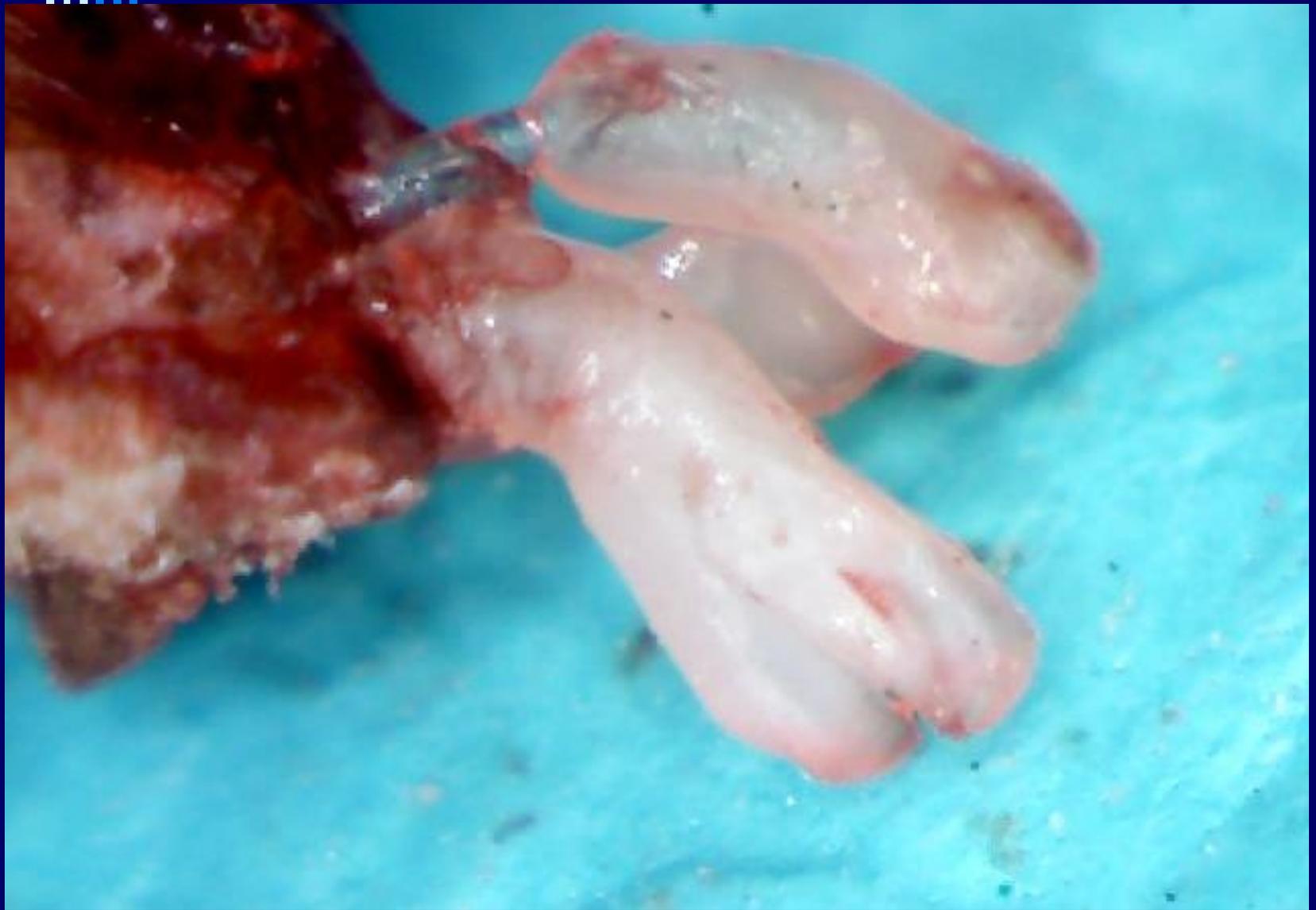


Keratin Projections under Thick Hard Scabs

- These “plugs” (as patients call them) gradually get harder over time and cause tremendous pain
- Patients dig at the scabs trying to remove them because they are trying to remove the source of their pain





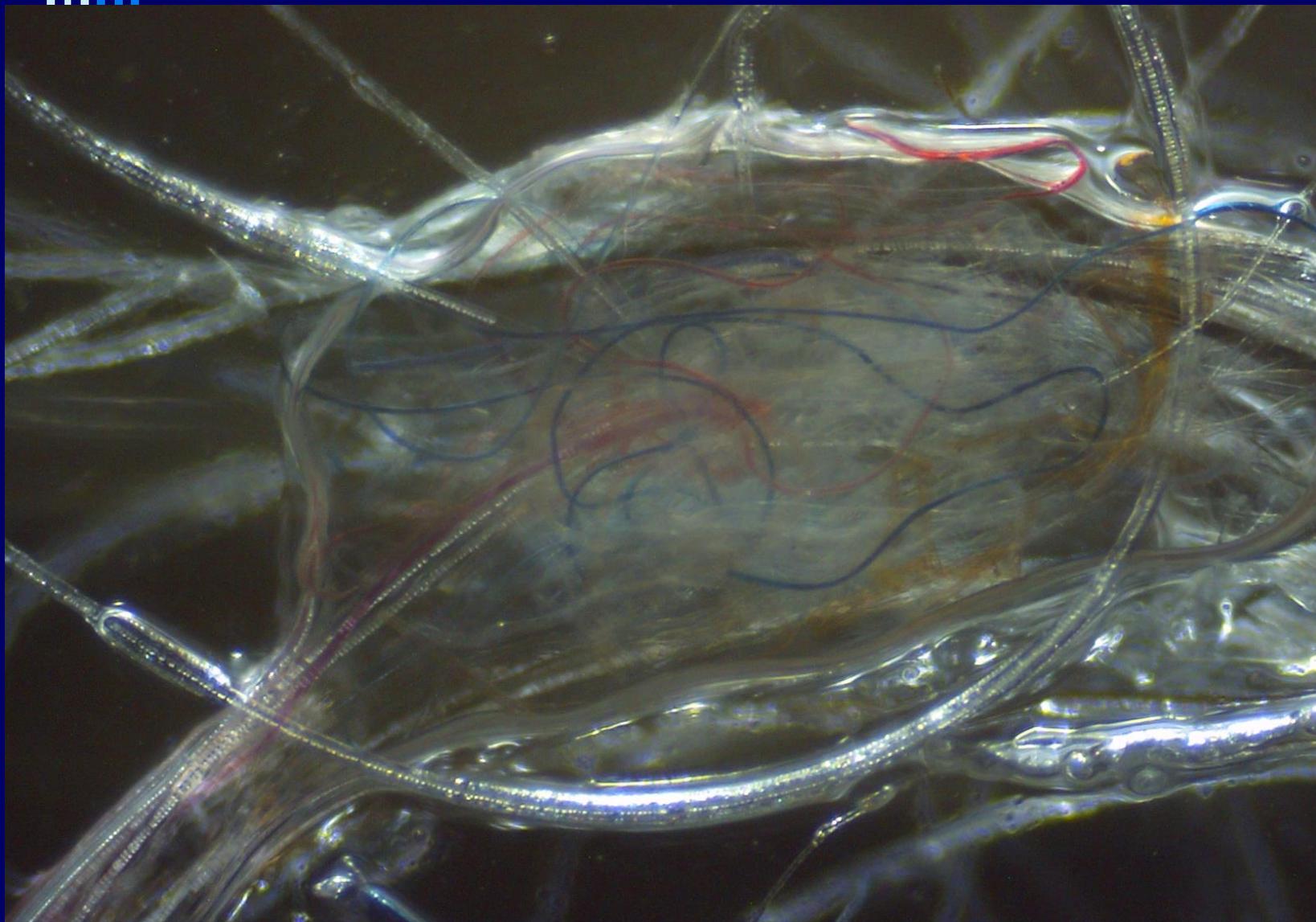


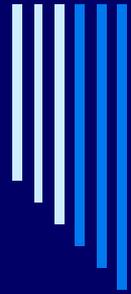












Fibers are everywhere....

- In the skin all over the body
 - In urine and in vaginal and seminal fluid
 - In the mucous membranes – eyes, nose, mouth
-



The Fibers Come From Every Orifice – This One, Vaginal







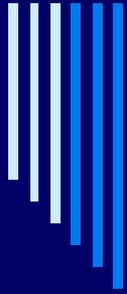
But Morgellons disease patients also have systemic symptoms.....

- Fatigue
 - Brain fog, mental confusion
 - Muscle aches
 - Joint pain
 - Insomnia
 - New onset of panic or anxiety
-



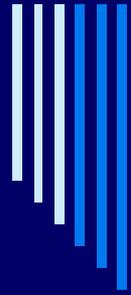
We are past the point of having to defend Morgellons as a legitimate disease

- These patients are **not** self-mutilating or cramming fibers into their skin!
 - The fibers can be seen under the skin with magnification!
 - So far the research shows an association with several different bacteria, particularly spirochetes
-



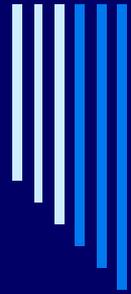
“In the face of obvious abnormalities, skepticism is inappropriate”

Richard Shoemaker, MD



What we know
so far

What we understand
about the signs and
symptoms



The Filaments (fibers)

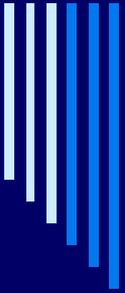
- ❑ NOT textile as many are claiming
- ❑ Are made of collagen (primarily) due to proliferation and activation of fibroblasts and keratin due to proliferation and activation of keratinocytes
- ❑ Some filaments are fine (smaller than human hairs)
- ❑ Others are thick and translucent
- ❑ Some are flattened and ribbon like



The Lesions

- NOT self-inflicted, appear spontaneously
- Very slow to heal – wound care experts try everything and nothing works
- Do not tend to get secondary infections with *staphyococcus* or *streptococcus*
- Sometimes lesions can be very deep leaving huge scars





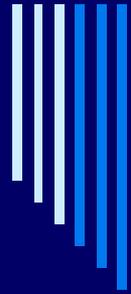






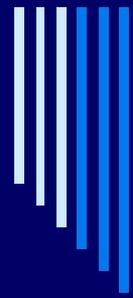
The Lesions, continued

- The following bacteria have been isolated from the lesions of MD patients:
 - *Borrelia burgdorferi*
 - Other *Borrelia* species including those that cause tick-borne relapsing fever
 - *Bartonella henselae*
 - *Helicobacter pylori*
 - *Treponema denticola*

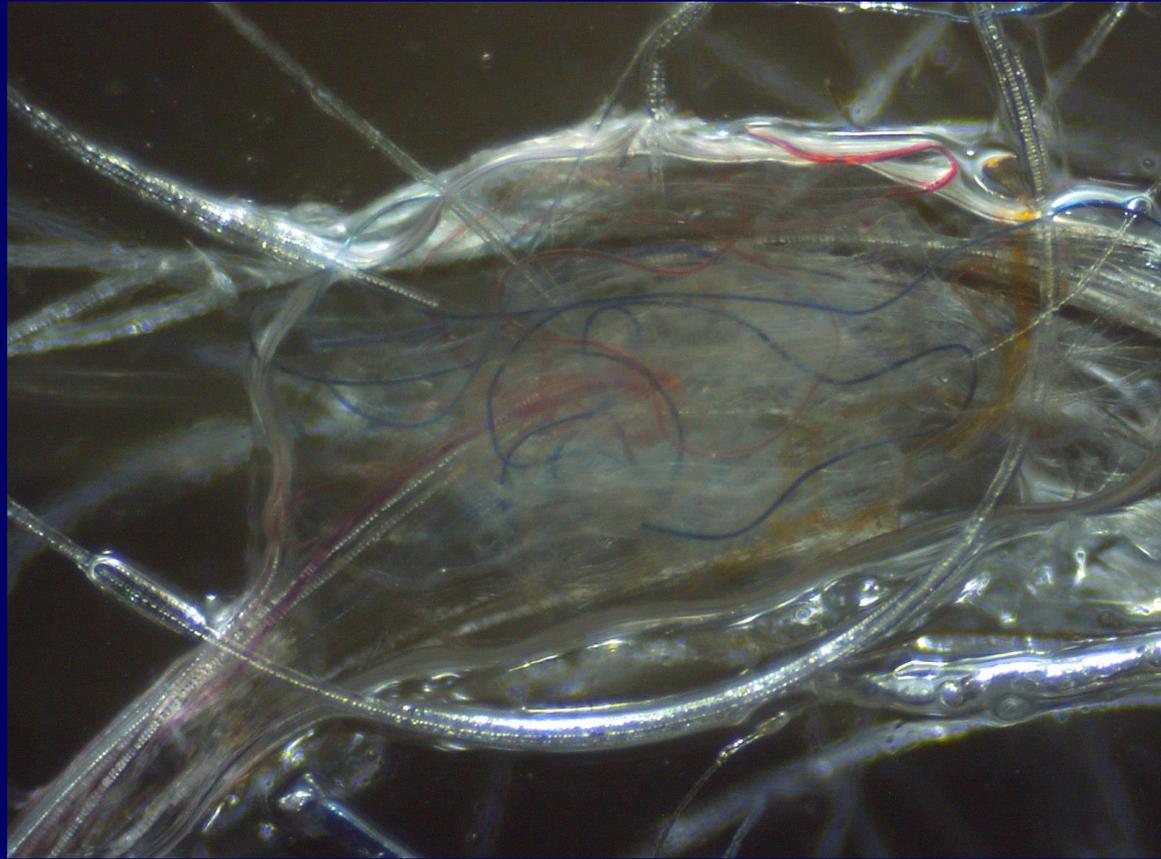


The “slime” or gel

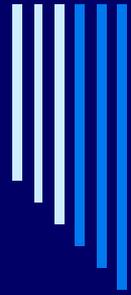
- Contains alginate, a sugar, one of the protective elements in the biofilm of the bacteria found in the lesions
- Alginate is gelatinous
- Found at the root of hairs in MD patients



Blue, Red and White Fibers in “Slime” that patients report on their skin

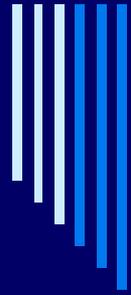






What we know so far

LATEST UPDATE ON
THE RESEARCH



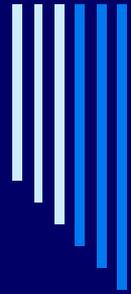
Randy Wymore, Ph.D.
Oklahoma State University,
Tulsa, OK, USA

- Cause of MD is NOT fungal
 - Collembola and *Stenotrophomonas maltophilia* can be ruled out as causes of MD
 - Agrobacteria are not the cause of MD
-



Dr. Wymore's Research, continued...

- ❑ Fibers are not textile or any other man-made substance
- ❑ Black specks that come out of the body are tightly wound up black threads
- ❑ Fibers coil tightly around hairs on the head



Wymore, cont....

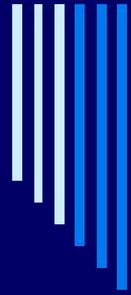
Isolated the following bacteria from lesions of Morgellons patients:

Bartonella henselae

Borrelia burgdorferi

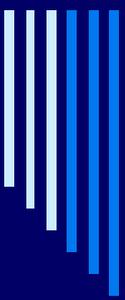
Treponema denticola

Helicobacter pylori



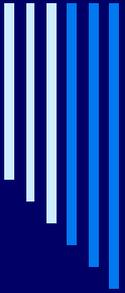
My Descriptive Study

- May 2010 edition of *Clinical, Cosmetic and Investigative Dermatology*
- First time that a study published in a peer-reviewed medical journal suggested an association between MD and Lyme disease
- Of 122 MD subjects, 97% tested positive for or were diagnosed clinically with Lyme disease



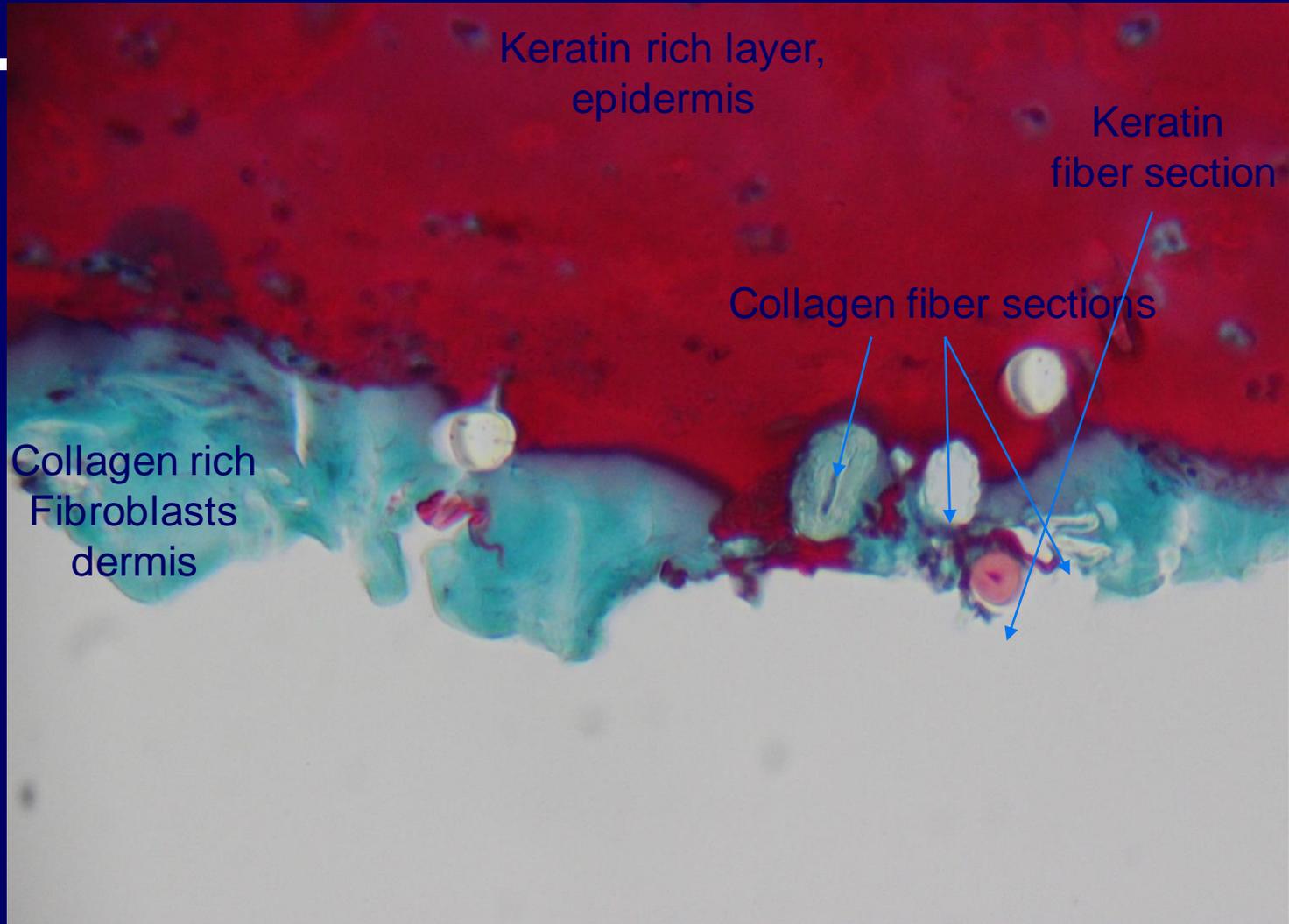
Marianne Middelveen

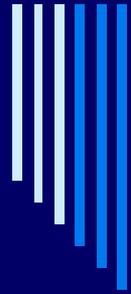
- Canadian microbiologist specializing in tropical and veterinary diseases became involved in research in 2010
 - MD reminded her of Bovine Digital Dermatitis (BDD), a spirochetal infection which causes ulcerative lesions and keratin filaments in cow hooves
 - BDD also causes lameness, weight loss and decreased milk production
-



Middelveen, continued...

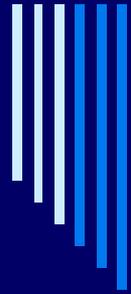
- She and colleagues published 5 works in medical journals between 2011 and 2015 supporting a biological basis for MD
 - These publications listed in References at the end of this PowerPoint
 - First to use *Gomori Trichome* stain showing that the fibers in MD are composed of the body's own proteins, keratin and collagen.
-





Middelveen, continued.....

- Using numerous different laboratory techniques, including cultures, *Borrelia sensu lato* were found in skin of 24/25 MD patients samples
- All 25 specimens showed *Borrelia sensu stricto*



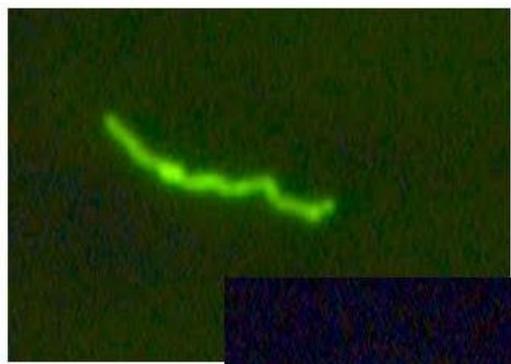
Eva Sapi, PhD

University of New Haven, CT

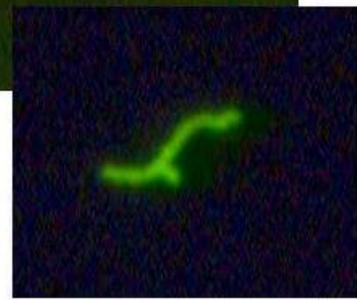
- Nested PCR (polymerase chain reaction), whole genome direct sequencing with metagenomic analyses, immuno-histochemical and in situ methods
 - Found *Borrelia burgdorferi* and *H.pylori* aggregates co-existing in MD lesions
-

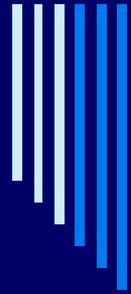


Monoclonal Ab



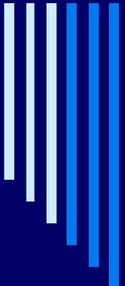
Polyclonal Ab





Important to note:

- Bb and H.pylori were the 2 pathogens isolated in metagenomic analysis of Morgellons tissue.
- Using the human DNA extracted from metagenomic analyses Dr. Sapi next plans to look for genetic variations common to sufferers of Morgellons



Studies regarding what % of Lyme patients get MD

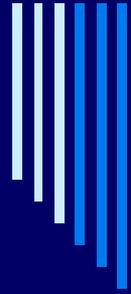
- 2 different studies – one by Peter Mayne, MD in Australia, one in the US by Melissa McElroy, FNP
 - Both show that 6% of Lyme patients also have Morgellons disease – some start with symptoms of both diseases together, others have MD symptoms later
-



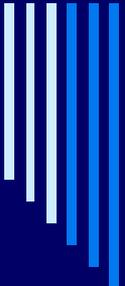
Jyotsna Shah, PhD

IGeneX Labs, Palo Alto, CA

- Pilot study of 10 MD patients
 - Hypothesis: There are other *Borrelia* species besides Bb associated with MD
 - All 10 were positive for some sort of *Borrelia* species – 7/10 were positive for one of the relapsing fever *Borrelias*
-

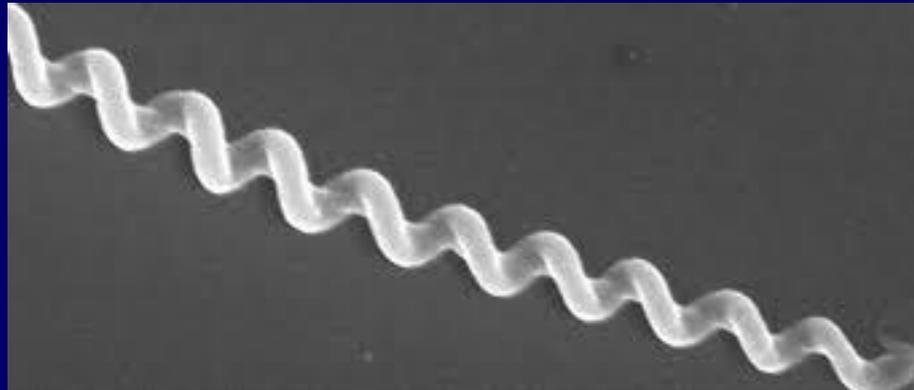


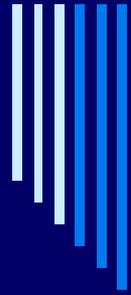
The Morgellons / Spirochete Connection



Spirochetes

- Long, thin bacteria in a coil shape
- A fraction of a micron in width, 5 to 250 microns in length

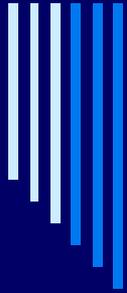




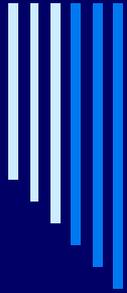
2 of the genera of spirochetes

- *Borrelia*
- *Treponemes*

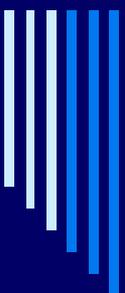
We will also include *Helicobacter pylori* as a spirochete— not technically a spirochete but it is spiral shaped and shares many characteristics of spirochetes so it is often included

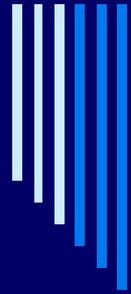


- Dr. Karl Axel Ekbom, Swedish neurologist, published a paper in 1938 describing 7 patients with symptoms that now resemble Morgellons disease.
- He was surprised to find that 3/7 had syphilis, caused by *T.pallidum*.
- Syphilis was very rare in Sweden at that time!



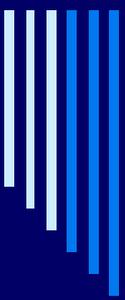
- Bovine digital dermatitis, cow disease similar to Morgellons disease is caused by a Treponeme, also a spirochete
- Wymore & team found 3 spirochetes in MD lesions: *Treponema denticola*, *Borrelia burgdorferi* and *Helicobacter pylori*

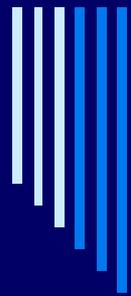
- 
- Dr. Sapi's group found 2 spirochetes: *Borrelia burgdorferi* and *Helicobacter pylori*
 - Middelveen and all found *Borrelia* spirochetes in 25/25 MD patients sampled
 - Dr. Shah found *Borrelia* species in 10/10 MD patients samples
-



The Lyme Disease Connection

Of all spirochetes there has been the most association between Morgellons disease and *Borrelia burgdorferi*

- 
-
- The connection with the spirochete *Borrelia burgdorferi* as first noted in my descriptive study where 97% of patients had Lyme disease
 - Morgellons patients almost all have systemic symptoms that are classic Lyme symptoms ; fatigue, malaise, muscle and joint pain, cognitive disturbances, insomnia, etc.
-



Morgellons fibers form from overactive fibroblasts (producing excess collagen)

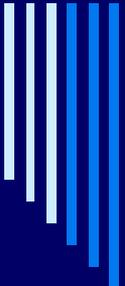
2 Klempner articles in 1992 and 1993 reported that :

- *Bb* can adhere to, penetrate and invade human fibroblasts
 - Fibroblasts protect *Bb* from antibiotics and provide a safe place for *Bb* to survive
 - Many studies show *Bb*'s affinity for collagen
-



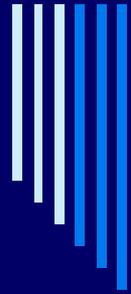
More on the association of *Bb* with Morgellons disease....

- *Bb* sensu stricto found in 25/25 MD patients in Middelveen's work
 - *Bb* sensu stricto found in 7/10 MD samples in Dr. Shah's work
 - Dr. Sapi has found *Bb* to be one of 2 pathogens in MD samples
-



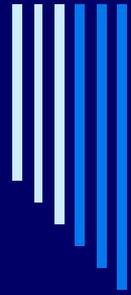
Is Morgellons disease a dermatologic manifestation of Lyme disease?

- It is tempting to think so because of all of these correlations
 - However, there are other things to consider....
-



The other side of the argument

- Correlation does not imply causation!
 - There are many dermatoses for which skin cultures are positive for Bb when the patient also has systemic Lyme
-

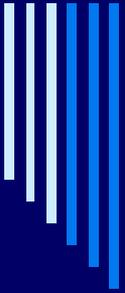


- Cutaneous sarcoidosis
- Prurigo Pigmentosa
- Granuloma Annulare
- Necrobiosis lipoidica
- Necrobiotic xanthogranuloma
- Erythema annulare centrifugum
- Interstitial granulomatous dermatitis
- Mycosis fungoides
- Lobular panniculitis
- Cutaneous scleroderma



Are all of these skin conditions caused by *Bb*?

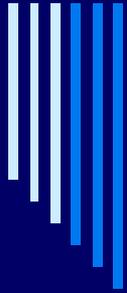
- *Bb* spirochetes tend to seek out weakened and injured parts of the body
 - In the case of the listed dermatoses as well as Morgellons disease – are these skin diseases dermatologic manifestations of *Bb*? Or are the *Bb* present in skin biopsies because of the systemic Lyme disease?
-



Lyme treatment does not cure Morgellons

- Treatment for *Bartonella* has much higher clinical efficacy
 - Interesting since *Bartonella* was the most abundant pathogen found in MD patients by Dr. Wymore's group and was also found in 3/10 of Dr. Shah's cohort
 - *Bartonella* also spread by fleas and many MD patients report flea infestation before symptoms started
-





If Bb causes Morgellons disease then why do only 6% of Lyme patients get MD?

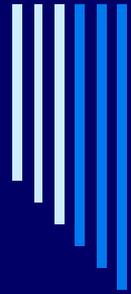
Strain variations?

Genetic susceptibilities?

Must be present simultaeously with another infection? (Such as H.pylori as suggested by Dr. Eva Sapi?



Ticks are CESSPOOLS of infection!!



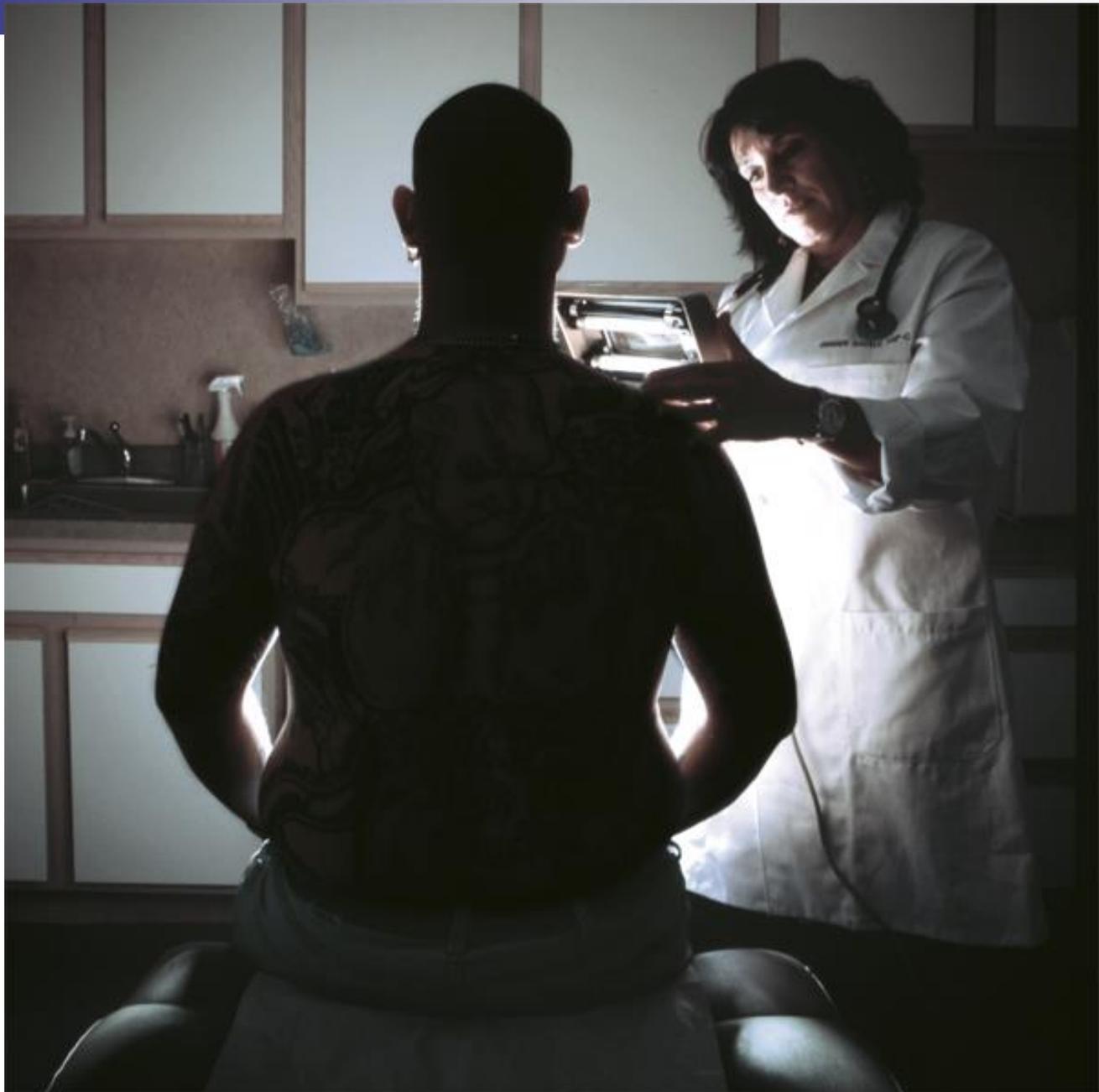
Ticks: Cesspools of Infection

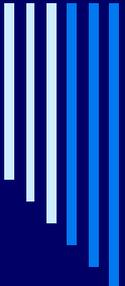
- ❑ Ticks carry and transmit a vast array of pathogens, such as bacteria, spirochetes, rickettsiae, protozoa, viruses, nematodes, and toxins
 - ❑ A single tick bite can transmit multiple pathogens, leading to atypical presentations of some classic tick-borne diseases
 - ❑ Morgellons disease may turn out to be a new tick-borne co-infection by a previously unknown pathogen
-

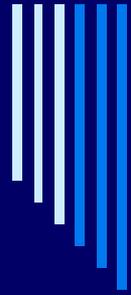


More Research Is Desperately Needed, but.....

.... meanwhile, what do we do with these patients who are suffering terribly and being told they are delusional?



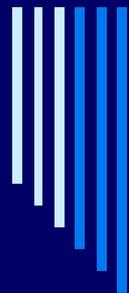
- 
-
- *Check for all tick-borne infections through a reputable specialty lab
 - * Then treat the tick-borne infections or suspected infections as you usually would
 - *Many of these pts have Bartonella even if they test negative – include Bart tmt
 - * In about 2/3 of these patients the Morgellons symptoms will improve by doing the above
-



What about the ones who are not helped by tick-borne disease treatment?

Email me and ask for my Morgellons treatment paper: LymeDC@gmail.com

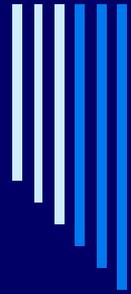
Treatment includes off-label use of other medications given at unusually high doses



My book on Morgellons disease
is available at this conference

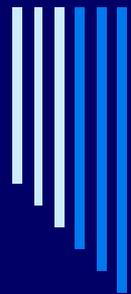
*Morgellons: The
Legitimization of a
Disease*

Dr. Ginger Savely



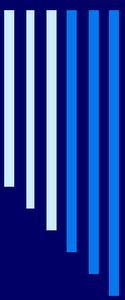
Important to warn patients!

- Just as the treatment of Lyme disease involves a Herxheimer reaction, there is a similar symptom intensification response to treatment of Morgellons disease
 - Sensations of crawling, biting, stinging, etc will worsen and fibers will increase in early treatment
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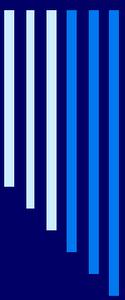
Informed Consent

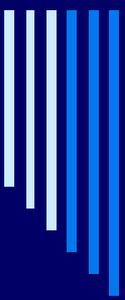
- Patients need to be informed that treatment for Morgellons disease is based upon clinical experience and is strictly experimental since the causative agent is still unknown
- Email me for a copy of my consent form (in English): LymeDC@gmail.com



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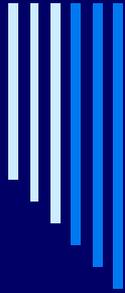
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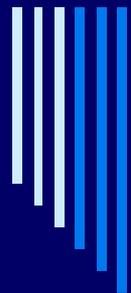
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For More Information on
Morgellons Disease ...

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