

*-Presentation for the Second Annual Morgellons Disease Medical Conference,
April 4, 2009, Austin, Texas.*

Hi everybody! Thank you all so much for being here today. My name is Amy Withington. I am a medical doctor, board certified in psychiatry and neurology.

I will begin my talk with my single most important message. If you remember nothing else from this talk, I want you to remember this:

I have NEVER met a person with Delusions of Parasitosis!

Everybody I've treated who was itchy had a real reason! However, I know quite a few people who were mistakenly diagnosed with "DOP". I should know because I am one of the many who was misdiagnosed in this manner.

Why am I here? To my knowledge I am one of only three medical doctors in the US who have Morgellons. I am honored that Cindy Casey, the founder of this conference, feels that I might have something to offer from my experience that might be useful to this unique gathering.

I will be telling you my personal tale in the hope that it might provide some helpful information for each of you. If nothing else, it may be comforting to some of you to hear a doctor acknowledging from her own experience that Morgellons is a bona fide disease.

Before I get to my story, I'd like to tell you a little bit about the region in France from which the disease gets its name. Then, I want to tell you about the life of a poet who may have suffered from this disease, as well as the experiences of a famous contemporary music star who is also a victim of this malady.

I find it very tempting to speculate about others who observed, or who might have had, Morgellons as a way of trying to understand my own experiences. When physician Sir Thomas Browne, in the 1600s,

described the “endemic distemper of children, in the Languedoc region of France, wherein harsh hairs break out on their backs, taking off the unquiet symptoms of disease”, his description exactly matches that of my first “crop” of symptoms.

A friend from France clarified for me that the region is known locally as ‘Morgelions’’. As long as we are all talking about the same condition, the pronunciation seems to be a “tomayto/tomahto” type of proposition.

My handy friend owns a Cultural Atlas of France, with photos of the region. The scenery resembles the rolling green hills of my native Massachusetts. Clues to the local flora and fauna can also be found in the ingredients of the best known regional dish. The ‘cassoulet’ is a heavy, white bean stew with goose, pork, mutton and sausage. Clearly, mammalian life abounded, and the accompanying vectors for disease may persist to this day, and play a role in what Sir Thomas observed, in a land with the same latitude and climate conditions as the northeastern US.

I was recently composing a note of encouragement to a friend just diagnosed with cancer, who was about to begin treatment. I sought out the inspirational poem that I loved from high school by Theodore Roethke called “The Waking”. It’s the one that starts,

“I wake to sleep, and take my waking slow”,
and ends,
“I learn by going where I have to go.”

Reading it again, but for the first time as a person with Morgellons, I was struck by his references in this poem to feeling the internal effects of the “tree and the worm”. As I delved further into his work and biographical data, I found the history of a sickly child who was raised tending greenhouses with his father and grandfather. Later in his life, this brilliant poet was beset by a complex set of un-diagnosable symptoms, including severe mood swings, for which there was no relief.

Quite a number of his poems contain Morgellons imagery and symptoms. Just the title of the poem “Epidermal Macabre” speaks volumes, and is about how his most fervent wish is to be rid of his skin!

In “THE SIGNALS” he wrote about the sensation of constantly having tiny mysterious objects moving at the periphery of his vision. His description does not sound like psychosis to me, but it resembles the sensation that I and some of my patients sometimes have, of small “hovering” objects at the edge of our vision, of which others nearby are unaware. Roethke’s poem concludes, “Sometimes the blood is privileged to guess/ The things the eye or hand cannot possess”.

If you enjoy poetry, I highly recommend his work. You will find a kindred spirit there. His death in the 1960s coincided with the rise of a musical genius who suffers from Morgellons.

Just this year, Joni Mitchell has chosen to share her experience with Morgellons with the public. Her empathy with this type of suffering is evident on her album “Turbulent Indigo”. Here are some selected lyrics from her song “The Sire of Sorrow (Job’s Sad Song)”, describing the torment of a man who has been covered with sores by Satan:

“Let me spit out my bitterness
Born of grief
and nights without sleep
and festering flesh.
I’ve lost all taste for life
I’m all complaints
Oh and look who comes to counsel my deep distress
Oh, these pompous physicians
What carelessness!
Breathtaking ignorance adding insult to injury!
They come blaming and shaming
And shattering me
Where is hope while you’re wondering what went wrong?”

Joni Mitchell, thank you for your courage in sharing your experiences and gifts with the world. This Amelia is eternally grateful.

And now it is time to tell you my tale.

Thanks to prime movers Cindy and Chas (who is here in spirit), this room is full of people who have all kinds of experience with Morgellons, from many different perspectives. When Cindy first made me aware of

my Morgellons diagnosis last October at the ILADS conference, she said “I can’t say I’m glad that you have it, but maybe if a doctor who has it will talk about it, others in the medical field might listen”. That’s why I am here.

I’m proud to carry on Dr. Gregory Smith’s tradition of sharing the experiences of a physician with Morgellons at this conference. Dr. Smith and Dr. Beverly Drottar are the only other physicians of whom I’m aware, that have Morgellons. They have helped to inform the public by sharing their experiences, and offering support to patients, in a variety of ways.

As with every person with Morgellons, each of us has different symptoms that are prominent. Each of them has some symptoms that I do not have, and vice versa.

In the case of Morgellons, it is likely that the devil is in the details:

- One, what coinfections the person may have,
- Two, what region of the country the person is from, and
- Three, the person’s unique genetic and family history.

My journey with discovering that I have Morgellons may bear some resemblance to some of yours. I grew up in MA, and had a tick bite and subsequent “bull’s eye” (or erythema migrans) rash in the mid 1970s.

The dermatologist thought it was ringworm, and gave the standard ointment. It faded gradually over time, but the “eczema” that I had had since childhood became much more severe. The patches sometimes occurred in my scalp, were extremely itchy, and produced a thick substance which caused my hair to become matted. As if the teen years aren’t challenging enough!

Through trial and error, I found creams and shampoos which gave some relief to the recurrent symptoms which would never completely disappear.

Arthritis is prominent in my family, and as joint aches and pains increased over the years I figured it was my familial cross to bear.

These symptoms would also wax and wane, and were usually manageable with common over the counter medications. After a period of extreme fatigue about 10 years ago (the kind where you wake up feeling like you never slept), I was diagnosed with hypothyroidism and started synthroid, with a little relief.

September of 2007 was a different story. I had crippling arthritis attacks.

At the time I did not associate these symptoms with treatment of the giardia I had unwittingly acquired in a Russian hotel swimming pool. The giardia symptoms resolved after the usual treatment with Metronidazole, but a week or so after finishing the prescription, the arthritis I experienced knocked me flat in the parking lot at work! I knew this was not the usual autoimmune progression and immediately suspected Lyme disease, given my history.

I went online, and my first few hits on Google took me to the IDSA guidelines. I dutifully self-medicated with the 3 weeks of doxycycline recommended and didn't find any change in my symptoms. During that time I saw my primary doctor who ordered an antinuclear antibody assay (ANA), a common rheumatologic screening test, and a Lyme titer. The ANA came back positive, and the ELISA Lyme titer was "indeterminate". When I saw my referred rheumatologist for the first time and told him my suspicions about Lyme and what the treatment and test results had been, he **said authoritatively, "then you definitely don't have it!"**

A number of other rheumatology-related lab tests looked at genetic markers such as double stranded DNA, Smith antigens, and the like. Most of the results seemed to point to the genetically-linked category of an "undifferentiated connective tissue disease". There is not much data in the literature about this somewhat vague diagnosis, but when I looked in its disease category, I felt more like I matched descriptions of Lupus, with:

- severe fatigue,

- sleep disruptions,
- skin involvement,
- hair loss,
- neurologic symptoms, including numbness and tingling in my hands,
- photosensitivity, and so forth.

The prescribed plaquenil (a quinine-based antimalarial, which I found curious) and the anti-inflammatory Etodolac seemed to help a bit with the joint pain.

Some of the other symptoms persisted and worsened, though, and I gradually began to suspect Lyme Disease again. This time I delved further into the online resources and discovered the website of the LDASEPA (the Lyme Disease Association of Southeastern Pennsylvania), and its remarkable chairman Douglas Fearn (who was just featured as an “activist hero” by the Under Our Skin organization, as he has arranged for numerous showings of this excellent film prior to its national release date in June).

At his website I learned more about Lyme and its coinfections and suspected that I might have Bartonella or Babesia as well, but screening tests failed to reveal anything conclusive. I was still groping for answers.

Last year, spring came early to suburban Philadelphia, and you might say I got a “wild hair” about improving the yard. I spent hours tearing up the hideous vines which were choking the plants and shrubs, fancying myself the Garden Gladiator, and baffling my husband who couldn’t understand why this activity was crowding out the numerous other chores which vie for the top of the “Honey-do” list when you have 2 young children and a fixer-upper house!

When I was done, my arms looked like I had escaped a terrorist interrogation! They were red, swollen, and covered with welts, despite wearing gloves and ivy block.

Vines have a way of finding an uncovered part of any limb!

Soon after, I drove to the American Psychiatric Association annual meeting in Washington DC and stayed with my sister. As I hobbled from the car on my swollen and aching feet, my sister looked at my arms and said “what happened to you?” I could only reply with a hangdog expression that I’d been practicing unsafe gardening! My response turned out to be a portent of what was in store for me.

Cracks and bruises abounded around my fingertips and nailbeds. I noticed that I was bruising very easily all over. Severe itching attacks which could last all night long became more frequent. My thyroid level became more difficult to control. I tried selectively eliminating the few medications I’d been prescribed, to try to rule out hypersensitivity, but to no avail. My rheumatologist was baffled too.

In mid-May, tiny lines of deep red with punctuate red spots appeared on my arms and legs and the itching and burning were terrible. Some of the spots turned into open sores that would not heal. These sores coalesced on my arms to form areas which looked like the photographs online of discoid lupus, raising that specter again.

I started to see tiny black specks and was horrified to suspect scabies. However, there had been scabies outbreaks at the public health clinics where I work in the past, and figuring, “eh, scabies happen” I obtained permethrin cream and applied it dutifully to myself and the rest of my family who had also started to itch. They got better immediately, but I got worse.

On a trip to the store between my multiple permethrin applications, I watched in disbelief as a “crop” of dark brown, thick hairs resembling a rubber-tipped fingernail brush sprouted on my left arm as it rested in

the sun in the open window of the car door. I had never seen anything like that before! We now know that Sir Thomas Browne did, in the 1600s, thanks to the research of Mary Leitaó. This young mother from PA was seeking any possible references in the medical literature for these same symptoms after observing them in her son about a decade ago, and the name Morgellons was here to stay for describing this condition.

But, being ignorant at that time of both my Lyme and my Morgellons diagnoses, I convinced myself that I was distraught, sleep-deprived, and must be mistaken. Since it brushed off, it had to have been lint which had somehow been trapped in the window frame and had chosen that moment to fall. There are times when the mind will grasp at any, semi-plausible, explanation.

However, as Pamela Weintraub would say, there was more... I must have applied a dozen topical antiparasitic treatments. I found a site for so-called “Norwegian scabies” online, which looked a lot like the white-crusted craters which had formed on my arms, and I started taking the antihelminthic medicine Ivermectin. My left forearm resembled a surrealistic pizza, and I developed circulatory problems and greater swelling of my hands and feet. Incidentally, I’d wager that research will eventually show that so-called “Norwegian scabies” IS Morgellons!

At this point, my desperation led me to a dermatology practice which could well be characterized as the Jekyll and Hyde team. There was a long wait to get an appointment for something as minor as persistent scabies. I took the first appointment, with the newest partner in the practice, for a month away.

In the meantime one of my patients, who has a chronic dermatologic condition herself, had pleaded my case to her longtime dermatologist—a partner in the same practice who had only limited appointment availability. When I didn’t hear anything for a couple of weeks, I figured that consultation was not meant to happen. During the 3rd week,

though, I got a call from her—she had a cancellation later that day, and could I make it in?

After making a minor schedule rearrangement, I hurried in. Dr. Jones listened carefully to my history, looked at the dark grains from my skin under her microscope, and said “I’ve never seen anything quite like this before. From what you’ve told me, though, if it was scabies, you must have

blasted them into oblivion. Maybe this is some bizarre residue? You can stop treating the scabies, but we should talk about what you are going to do about your chronic Lyme disease”.

I was stunned. This was the only medical professional who had ever shared my suspicions. She revealed that she had had Lyme meningitis and had needed 3 months of Doxycycline treatment, rather than 3 weeks, so I resumed taking Doxycycline immediately.

I’m very grateful for that diagnosis which started me on my own journey of discovery. I read everything I could find about chronic Lyme disease. I felt very well informed for my other dermatology appointment a week later, which Dr. Jones suggested I keep for quicker followup.

Everything that went right with the first visit, went wrong with the second. I waited over an hour past my appointment time. Dr. Vomer unapologetically hurried in with a medical student in tow (which was a surprise to me), reading the chart as he entered the room. Remaining on the other side of the room he said, “so you’re here for a scabies followup?” I said, “Well, Dr. Jones and I thought at first it might be scabies, though the residue didn’t look like anything she had ever seen. I’m worried that the skin symptoms aren’t any better, and we’re treating the underlying Lyme disease”.

His feet steadfastly planted in place, he said “have you been picking at your arm?”, dubiously eyeing the raw patch on my left arm. I said, “I’ve been trying to avoid that, but I did pull out a few black threads which seemed to be stuck in there under where the bandaid was, interfering with healing”.

Dr. Vomer now looked like he had a firm diagnosis. He turned to the medical student and said “Let this be a lesson to you. **The diagnosis of Delusions of Parasitosis does not exclude psychiatrists. You can finish the note**”. He strode from the room.

Once again, I was stunned. However, as the baffled-looking medical student began writing, I said, “the true lesson is going to be when you learn what is really involved in chronic Lyme disease.” She smiled and shrugged, clearly caught in the middle. I resolved that I would never make an appointment with Dr. Vomer again, but I have sent information on Morgellons disease to his office since then, and plan to send an update in the near future!

Undaunted, I went to the fantastic local presentations in my area last September by Dr. Joseph Burrascano and Pamela Weintraub, where I learned of the LDA and ILADS Lyme disease conferences set to happen in San Francisco in October. I wept for the entire hourlong drive home, for the realization that my 3 months of Doxycycline were over, I was not much better, and that a cure was very unlikely for me and for many others in that packed auditorium. I also knew that I had to get to those conferences if I wanted more answers.

By the time I got to San Francisco, I was suspecting that I had a Bartonella coinfection based on Dr. Burrascano’s presentation, and the curious red lines which would appear in strangely curved patterns on my skin. The first day of the conference, I saw Cindy Casey, RN at her booth with its Morgellons poster, among the many other booths with useful information about related conditions and products for people with Lyme Disease.

I rolled my eyes at my own ignorance, thinking, “what now, what other esoteric condition can be associated with Lyme Disease?” and approached the booth.

THIS time, being stunned felt like a thunderbolt! I looked at Cindy and said, “I had no idea that any other person on the planet had experienced

this but me. I'd become convinced that there was no point in saying anything more about it because there was nothing to be done except risk ridicule!"

I looked on in mingled horror and fascination as Cindy used her handy scope to fluoresce the fibers within my arms that rival the appearance of the

Illustrated Man on the cover of my favorite collection of Ray Bradbury science fiction stories. Fitting, no?

I feel so fortunate to have met Cindy when I did. I could literally brush off the first episode of intense itching and skin eruptions in the Spring with an unlikely (but not impossible) explanation. However, I would never have been prepared for Round II which occurred in November, with a fantastic panoply of shapes, forms, colors and textures. I couldn't have come up with a plausible enough delusion to cover the production of all of those!

I am fortunate in many ways. My symptoms so far have not been that obvious or disfiguring (I think). Arms and legs are easy to cover, but facial lesions cannot be ignored. The worst of the lesions do leave prominent scars, and attempts to explain them can be awkward.

I have been able to find the information I need, to pick up my research where my medical team's knowledge leaves off. I have been trained in "medicalese", due to my profession. I've been able to self-diagnose some of the coinfectious conditions, and usually can get the necessary medications. Although my Lyme Disease diagnosis took over 30 years, I am much more fortunate than those whose journey to the diagnosis of Morgellons has also taken many years. Some patients do not survive that journey; for some, suicide seems the only deliverance from ridicule, shame and misunderstanding.

I've only been diagnosed with delusions of parasitosis once, and had the luxury to walk away and never return to that doctor. Although Dr. Vomer, my "bad" dermatologist, may never review the information I

send his way, he did give me a valuable insight into how being diagnosed with DOP really feels.

Dr. Jones, my “good” dermatologist, at a later appointment, was willing to receive and to review some articles and the DVDs of this conference from last year. Even my rheumatologist, who says he does not believe in chronic Lyme (yet) and had never heard of Morgellons accepted and said he would read, a copy of Savely and Leitao’s elegant article on DOP and Morgellons, and Dr. Stricker’s great overview of chronic Lyme disease which appeared in last July’s Journal of the AMA. That’s all I can probably ask of my own medical team for now, and that is enough, for now.

It is enough because I feel I can now draw on the expertise of the active ILADS and Morgellons communities for information updates, reality checks, and constant striving to understand the scope and complexity of these baffling conditions. Dr. Wymore’s research sets a national standard. Douglas Fearn has helped me make inroads in raising awareness in my local community, as when he helped arrange for Dr. Ann Corson to present a riveting Grand Rounds for our hospital department.

That timing was wonderful because it coincided with the date of the NIH recognizing Morgellons BY NAME as a REAL Lyme-associated condition! On January 28th, I was thrilled to distribute that update at our grand rounds. We may have been the first large group of psychiatrists to get the word that Morgellons is real! I was also in the unusual position of being the first to inform Douglas Fearn about anything, and he said, “Now it looks like we are getting somewhere with this !”. I am certain that everybody here, in some way, had a hand in the NIH recognition.

It is vital that we keep communicating openly with all of the people committed to researching this condition and to providing relief for patients!

The more I live with this condition, and the more research I do, the “curiouser” it gets, to paraphrase Alice in Wonderland.

I certainly do not know exactly what causes the condition. I suspect a number of different factors may be involved. My own “skin sculptings” have exhibited a Salvador Dali-esque variety of shapes and forms, many of which are selectively cited by opposing sides in debates over the source of the symptoms! Early in my first outbreak of skin manifestation, I had tiny insect parts emerge, including wings! There is a consistent production of fibers in shapes ranging from tiny stumps to tangled cords. These white, brown, red, blue and black fibers emerge like a sculpture garden after every shower. There have been tiny clear crystals. There have been rare episodes of something that looks like a biofilm, and crusting. There have been rows of tiny red lines, which led me to suspect Bartonella coinfection. There have been tiny, hexagonal, shiny metallic objects, but not many. I have a great collection of filled matchboxes if anybody would like to see them!

One of the researchers at this conference last year, Mark Darrah from Dr. Citovsky’s lab, questioned whether the waxy material might be attracting “schmutz” from the environment to stick to the skin. That has not been my experience or that of my patients. As I mentioned, it happens in my case when I am completely showered and toweled off, with lint-free towels. In my case, extrusions happen from the skin, and I can observe the process.

Mr. Darrah mentioned seeing one of last year’s conference attendee’s fibers moving. So far, just one of my patients locally has reported seeing that. I cannot say for certain that it has happened to me—yet!

But it is invaluable to me to hear these reports and theories. There may be some people with Morgellons with very waxy skin who can attract particles from the environment, and their risks may be different. There may be motile fibers which are more prevalent in one part of the country than another, or arise after certain exposures.....

The majority of my fibers tend to resemble cellulose-like material. One of my patients developed the same type of initial “crop” that I did on her check after she bumped into a tree branch with it. Our ‘output’ (hers and mine) seems to have been triggered by an initial ‘input’, from the

natural environment. It was not a process of attracting stray particles (in our cases), but of a direct encounter with plant life. I believe agrobacteria is involved in my case, and in my patients', but there may be many other things involved too.

Since bioengineering has “gone wild” (now there’s a theme for a Discovery Channel program) couldn’t other types of organisms, bacteria, parasites and viruses be exchanging genetic material or cooperating in bizarre combinations previously unseen in history? We have some precedents, such as were set down in writing by Sir Thomas Browne and possibly Theodore Roethke. I have wondered if any clues to Morgellons’ creative process could be found if we understood better the bizarre combinations that are found medically in hamartomas, also known as dermoid cysts. These usually benign tumors can grow quietly for years, and can contain several teeth, tufts of hair, an eyeball, fingernails—any combination imaginable of the end products of human embryonic skin cell differentiation, combined seemingly without any rhyme or reason. What do you suppose is the “prime mover” in that process? Of course, hamartomas grow internally, whereas Morgellons appears to manifest itself primarily on the skin surface, but they share the surreal qualities of formations previously unseen in science...

Our environment now has completely foreign compounds from:

- pollution,
- toxic waste,
- biowarfare,
- genetic engineering,
- the thinning ozone layer and
- global warming --- just to name a few!

What if some of the Morgellons reaction is adaptive? Could the mutant mechanisms dwelling in our dermis be processing pollutants, packaging some of them in waxy structures which make them easier to push out? No one can say for sure, but I am sure that if we keep communicating, we will make substantial inroads for understanding and relief.

My relationship with my patients is very collaborative—I think I benefit from their experiences and knowledge as much as they benefit from mine. I treat a pair of identical twins who are both in the health professions and are interested in participating in research, so I'm putting out the word here.

My horizons are constantly expanded and reshaped by my patients, by all of you, and by those who have gone before. My family have been amazing partners on this journey. I'm glad to be able to tell you that their health is pretty good. They have all had some Bartonella and possible Morgellons symptoms, but I believe I am the only productive "sculptor" in the family so far. Across the board, Bartonella in each family member seems to have responded to antibiotic treatment, and our chief suspect for its source remains the rescue cat who came to us with a raging ear mite infestation two years ago. I do worry about my sons' prenatal exposure to Lyme disease at times, and feel I can recognize signs that might require treatment and referral to an experienced Lyme-literate clinician.

After the initial scabies scare last Spring, we resumed life pretty much as usual. We're a family of huggers. I don't think I infected them with Morgellons. We all got itchy at the same time. They got better much sooner than I did. Based on my own experiences, and those of my patients, I doubt that most cases of Morgellons, even those that may have a parasitic component, are any more infectious than demodex mites would be considered infectious between people.

In my experience, you're either vulnerable to Morgellons or you're not, and even if you avoided contact with every other human being, you just might walk into the wrong tree branch some day! Still, I have patients who literally agonize over feeling they cannot hug anyone in greeting or have intimate relationships. I cannot prove which of us is "right". I do ask them to consider that there has been some online discussion recently about magnetic polarity, and possible attraction and repulsion of Morgellons skin elements based on electric charge. I've noticed that I itch more when some of my patients are around. This is not

insurmountable and is usually temporary. I have not had the sensation of getting any further infection when I am in their presence or afterward (and vice versa).

My philosophy is, YOU HAVE TO LIVE YOUR LIFE!

During the Stalinist repression, the Russian author Mikhail Bulgakov wrote that “the lover ultimately, willingly, takes on the afflictions of the beloved”. Whether or not everyone in the family has Morgellons symptoms, they all travel the road together, as Cliff Mickelson writes and sings so eloquently.

Why not reap the benefits of taking that journey together also? Hug the ones you love, and if you love the outdoors, don't hide from it out of fear. There is relief available for Morgellons and for all of the associated chronic conditions. There is no reason any of them have to be fatal. If you haven't found someone who will work with you to find your unique medical solution (and it will have to be individualized with a condition this complex), I implore you to keep looking. There are some great opportunities to make a connection in this room right now, or on the NMO (New Morgellons Order) web site.

I'll leave you with the following words to ponder. This from Thomas Henry Huxley, “Sit down before fact as a little child, be prepared to give up every preconceived notion, follow humbly wherever and to whatever abysses nature leads, or you shall learn nothing.”

And from Robert Frost, “Nature is always hinting at us. It hints over and over again. And suddenly--- we take the hint”.

Thank you all, very much, for your time!