

AmyL Frankel MD: All right so I'm Amy Lynn. I am one of the first year residents and this is a talk called "When Good Bugs Go Bad" and I hope you all had a chance to talk with the patient across the street. So I have nothing to disclose.

This patient is a 44-year-old healthy woman who comes in complaining of bugs, that she's infested with bugs. She has got no real significant past medical history. The only very interesting thing is that she has a Factor XI clotting deficiency, which doesn't bother her at this point but in the past has required some transfusions.

She is the mother of two. Lives at home with a husband and is a fairly active person. So the story begins in October when she began to feel an itchy crawling sensation on her scalp. She suspected lice after seeing a bug fall out of her hair and having two kids who had lice before, she thought that that was pretty normal. So you she tried a RID treatment and a comb-out and hired two different lice companies to come into her house, treat her, her children and her husband and take a look around for lice. And they found nothing.

After the treatment, she continued to find the bugs. One of the companies returned for a second treatment of herself and her entire family. Again they found nothing. She still continued to feel that itchy sensation, would go to the tub, shake her head out and a bug would fall out. Usually one, maybe two bugs at a time. One of those times she witnessed the bug jump, much like a flea would so she thought maybe this is fleas. She doesn't have any pets but she does live in a New York City apartment building and there are tons of animals around all the time.

So she went to an outside dermatologist, they gave her Ulesfia which is a treatment for lice and Ivermectin and despite the treatment, she continued to shake out the bugs, pretty much nightly, out of her hair. At this point, she started doing her own research and used a lot of home remedies. She did olive oil under occlusion for nine hours overnight. She did mayonnaise for overnight. Tea tree oil, Denorex, and a bunch of other treatments. She collected one of the bugs and showed it to one of those lice companies. They said it's not lice but we don't know what it is.

So this is a picture of the bug that she collected. It's tiny. You can see right there. There's another picture. And there's another picture. Now when she comes into the office and we look at her head, we don't actually see any bugs, but she's bringing us these bugs wrapped in tissue paper that she has found coming out of her head. So she very interestingly enough brings the bug that she collected to Louis Sorkin, who's the senior entomologist at the Museum of Natural History and he immediately identifies the bug as Collembola or Springtails.

She continues to have exterminators come looking for bed bugs and other bugs in her apartment. They do everything they need but they don't actually find any bugs. She continues her own remedies and now she begins to feel this light crawling, popping and biting sensation throughout her entire body, not just on her scalp. And she describes it as also under her skin. And she also has this overwhelming intermittent

itchiness on various parts of her body so the symptoms are escalating.

So three weeks after the appearance of the first bug, she takes a second dose of Ivermectin. When she finishes that dose she does about a week free of finding these bugs but the night before she came to see us, she found another bug. So that was one week after the Ivermectin. So this is our patient's scalp. It's probably not easy to see but you can't really see anything. We decide to do a biopsy when she comes in a second or third time saying this is tender right here, I think there's something right here. So we did that biopsy and it didn't show much. Basically a superficial pustular folliculitis. And this is where we took the biopsy from.

So just a little bit about Collembola. Collembolan fossils are basically prehistoric. They're among the oldest known records of them from the Devonian period. They're basically ubiquitous in terrestrial systems. They're small, one to five millimeter wingless, Entognathic Hexapods and they have antenna. And they have this ventral appendage called the furcula. And they generally inhabit moist environments which may contain decaying organic matter and organisms like fungus.

So these are a picture of Collembola that I got off the Internet from the NPA which we'll talk about in a second. And not from the patient but as you can see, the bugs look the same.

So the National Pediculosis Association, or NPA, has spent a long time looking at cases of Collembola in addition to lice. And they compiled a registry of these cases that didn't really fit into scabies, and didn't really fit into head lice and they started noticing a trend that maybe there was something different out there that was acting similar to these bugs but not being treated appropriately. And all these patients had a few things in common. They all complained of symptoms of crawling, stinging, biting, and burning on the skin with intense itching. Sometimes they would excoriate themselves and get ulcers and most of these patients were diagnosed with delusions of parasitosis.

In their paper they identified 18 out of 20 patients that had Collembola but the paper was thrown out for various ... or not thrown out but controversial for various reasons which I won't get into. But the bugs weren't actually found on these people in all cases.

So historically Collembola are thought not to be capable of parasitizing humans which is why there's such controversy surrounding this topic. Like I said, there's several case reports of human dermatitis, allergy and crawling sensations where Collembola were identified but not physically on the patients so it's unclear whether these represent true cases of an infestation or a human skin reaction to Collembola or just an incidental finding.

And the big question is can they bite because one researcher did demonstrate that there was blood of newts and toads in the guts of these Collembola indicating that

they can indeed bite despite the fact that their mouth parts, which are within the buccal cavity seem like they shouldn't be physically capable of biting humans. That research has been around since the 40s, that they're just incapable of biting. But it's possible also that that furcula that they have on their ventral surface allows them to spring, hence their Springtails. So it could be that the springing is causing the dermatitis in some of these patients or local allergic response.

So this is the video. Let's see. I don't know if it's going to work. It's not going to work. Okay. There was a video of the bug crawling. We didn't catch it jumping but these bugs are indeed alive.

So the big question is, is this delusions of Parasitosis or is it a true infestation because up until this point, we have not been able to identify a bug in our patient. I've spent a lot of time with her. I've looked at her scalp. I have not been able to see anything and she hasn't been able to shake it out for me but Louis Sorkin visited her home and she physically shook out a bug while he was there, I believe. She always brings in the bugs in these little plastic bags. So when we get to it, it's not working.

So she finally got frustrated with me and my inability to find the bug and she went to a medical photographer and so these are actually from January 23rd and it looks like this might indeed be a bug. I can't say it's not. And here. And here maybe. So because they're so difficult to identify, the NPA has come up with this protocol to try to help practitioners and the patients because it's such a frustrating disease. So they recommend combing out your hair, swabbing your scalp, skin scrapings, biopsy. All of which we've done with her and so far, no luck.

So why we brought her here today is how do we eradicate an infestation of an organism not known to infest humans? Because the literature is so scant, there's really nothing in there that has helped us. There was a study that showed that antibacterial agents like Metronidazole were not shown to be effective in our patient. We used anthelmintics, Ivermectin not efficacious. Diflucan, we thought maybe since they live on fungus we could treat her with Diflucan. We gave her two, three day courses that also failed. There were some things in the literature I saw about temperature variance.

D.Z Altschuler: What?

AmyL Frankel MD: So my thought is maybe freezing or heating. I'm not quite sure at this point here. She's really, really frustrated.

Mark Lebwohl MD: So our usual [inaudible 00:09:25] has really presented the patient. As for differential diagnosis, you all would have said she has delusional parasitosis. And then we would have shown you the photos. You know, it's interesting that when you go to doctors and they can't find treatment or diagnosis, they tend to call the patient crazy. And those photos are pretty impressive to me. And she always brings in these bugs. Unless she has a farm of Collembola, I'm not sure where she's getting them from.

And certainly, when you saw her in the office with me, it sprang. I mean it jumped like a foot off of the ... We put it down on the stretcher. We thought she was nuts and this thing just jumped. So I do believe this is real. So any suggestions for therapy?

Male 1: How about some type of insect repellent on the patient? Has that been tried?

AmyL Frankel MD: That has not been tried. Like a DEET product?

Male 1: Like DEET or similar. Some of the safer ones they have now.

Mark Lebwohl MD: That's a great first idea, yes.

Female 1: Just working on that, if they can jump around that much and you're not always finding them on her and are sometimes finding them on her, one would think there's a reservoir someplace that we're not thinking of. Like when they come into the house and they can't find them, they're probably looking in typical lice places. I'm thinking about body lice that end up in the seams of clothes. Has somebody checked seams of clothes? Maybe they're jumping from, I don't know, the floor of her closet? I think that maybe the examination of her home might have to be expanded.

Mark Lebwohl MD: She said she had her house fumigated.

AmyL Frankel MD: She had her house fumigated several times and the entomologist from the National Museum of History, I think got on his hands and knees in her house and looked at every crevice including the bathtub drain where she shakes the bugs out and they didn't find anything.

Male 3: [inaudible 00:11:20]

Mark Lebwohl MD: So that's true, you get a lot of bed bugs. And that's actually a thought and there are ... It's very expensive, costs a few thousand dollars. You've got to take everything that's plastic out, and that's one of the current treatment for bed bugs. Now what the problem is, it's expensive. We don't know that it worked for this, but it's actually worth to try, so we came up with a good list-

AmyL Frankel MD: And she also went away for a couple weeks and though that she would not find any. But she did.

Male 3: We have to make sure that the apartment [inaudible 00:11:58]

Mark Lebwohl MD: When she went away for a couple of weeks, did she find them where she went to?

AmyL Frankel MD: Yes, she still continued to shake them out.

Mark Lebwohl MD: I see. Okay. Alright.

Male 5: I was just going to suggest that, perhaps [inaudible 00:12:12]

Mark Lebwohl MD: Yeah, you're one of those doctors in the papers. This is Bertie Owens.

Female 2: No one else in the family has it?

AmyL Frankel MD: Nope. Her children and her husband don't.

D.Z Altschuler: They're asymptomatic, that doesn't mean they don't have it.

Female 2: Well, that was my question. How many household members are there?

AmyL Frankel MD: There are two children and one husband.

Female 2: Okay. And so if we're going to buy that this is real, then why do they like her so much? We should have her change all her personal care products that might be scented. You know, shampoos, conditioners, body lotions and all of that. And because there's some reason they like her better than they like the other family members. And I would suggest as a treatment, 5% precipitated sulfur.

Mark Lebwohl MD: Okay, so you've got a good list here. That's an old, old treatment for lice.

Female 1: It's drastic, but honestly she should cut her hair.

AmyL Frankel MD: She's willing to shave her head.

Female 1: Shave her head and see [inaudible 00:13:12]

Mark Lebwohl MD: Okay, so we're coming up with first, second and third line therapies that bear in mind, would actually certainly have occurred to me. And if I were in her position, who would open the ... Of course to me, it doesn't matter.

Female 1: Ivermectin [inaudible 00:13:32]

Mark Lebwohl MD: The risk of Ivermectin's probably not much.

Male 2: It was not clear, during when she was on Ivermectin, did she get any relief? Because to say it was a failure, it's not clear to me whether it was reinfection, reinfestation, or failure.

AmyL Frankel MD: According to the patient, the first time she took it there was no change. The second time she took the dose of Ivermectin there was a week of having no bugs. And then they came back.

Male 3: [inaudible 00:14:00]

AmyL Frankel MD: I'll have to check. It's a standard [crosstalk 00:14:08].

Mark Lebwohl MD: Sorry, for what?

Male 2: For lice, for lice [inaudible 00:14:13] So she may [inaudible 00:14:18]

Mark Lebwohl MD: We can give her more ... That's an easy first low dose. You might do that at the same time you do the Deet. And some of the other ... Heating the house is very expensive, and it's probably not going to work because of when she went away, it didn't help. What about ispum?

Male 2: That's PL Ivermectin.

Mark Lebwohl MD: Yes

Male 2: Are they trying a topical formulation now? Is there one available?

Mark Lebwohl MD: I'm not sure.

Male 4: No, there's not one available, but they've studied it for head lice in the 1%, and it works pretty well actually.

Male 2: Because, in order for the PEO to work, the organism has to be feeding, doesn't it?

Male 4: That's right.

Male 2: Yeah, so why not try topical?

Male 4: The issue here is ... You first have to decide, is this real or is this not real? And if you think it's real, then you also have to understand that this is something that's not really describing for it. So we're attributing all the treatments and biology assumptions of head lice to this new organism, and that's probably not the right way to go about it, since it's not an easy fix. So I think the first thing we need to do is understand where does this thing live normally? Where would a reservoir be expected to be? And if it's really just in this person, why isn't it in other people? And then in vitro tests about what things kill this. What's the entomology literature on this insect, about how they eradicate it in whatever situation it's normally encountered in?

Mark Lebwohl MD: So we have one of the world experts on Collembola here and actually I assigned that to her, and she thought of extremes of temperature. Liquid nitrogen. And by the way has she gone to a hair parlor where she-

AmyL Frankel MD: I actually told her last week that that would be a good idea. Because we can't get anything hot enough if she sat on her hair.

Male 4: How big are the eggs? What's the life cycle? How long do they hatch?

Mark Lebwohl MD: Well we can write an encyclopedia about it, but we do want to help her too. [crosstalk 00:16:09]

Male 4: That's part of the thing is, if you're going to give her an oral thing, and they feed on the blood-

Mark Lebwohl MD: Of course, but to call her crazy when she has this martian in her hair, that she's photographed with a computerized device. And actually showed it to a medical photographer. That really looked like the organism in its shell. Now part of this is I believe psychological. She's proven nuts by the fact that they're in her scalp. Even if they weren't causing any other real symptoms, the knowledge that it's in her scalp is driving her crazy. And so I think that we have to help her get it out of her scalp. And I think this is pretty convincing that they are on her scalp. How do you think she got them there?

Male 1: I just think they're probably more ubiquitous than we're really aware of. And since she's having symptoms she kept [inaudible 00:17:03] it doesn't prove that it [inaudible 00:17:09], whatever that is. I still would offer her a psychiatric evaluation, if she is willing to go through the whole thing. A lot of these patients are either depressed or obsessive-compulsive. And sometimes [inaudible 00:17:24] or something, where that can be mainly effective if we can get her to a psychiatrist. Speak whatever you're doing, she probably would do everything else.

Male 4: Well I would say if she's willing to go see a psychiatrist, it speaks against Morgellon's disease, because they often are adamant that they are not crazy.

Male 2: We'll have to diagnose her disease, but-

Mark Lebwohl MD: Why don't we have that conversation when we speak to the psychiatrist too. I certainly am convinced that this is real. Yes?

D.Z Altschuler: My name is Deborah Altschuler, may I speak? I'm from the Pediculosis Association.

Mark Lebwohl MD: Oh, sure.

D.Z Altschuler: I would like to agree with the past two comments that were made, that there's a lot we don't understand about this organism. And if we do study the organism, we can find that it is used by our government, because it is so resilient as a test animal. And our experience has been that the more we throw at it, or the more people throw at it, the more vigorous it becomes. So it is counter-intuitive. It's not like what we would expect in traditional methods and certainly the way in which people are approaching

it as head lice is probably more accountable for sales of lice treatments than anything else.

I would also just like to right the record a little bit in regard to our paper. That the journal that published our paper has made a statement that they will not be retracting our paper, because of one accusation from a graduate student in California where the idea of delusional parasitosis is entrenched. They asked him on two occasions to provide evidence of fact that our images were not accurate and that there was something false about our work. And he could not provide that. The paper that we published was a baseline opportunity from the center of the world, where people who never had the opportunity to report their problem before had a toll free number. And when they started calling us, we very quickly ... And the staff certainly were not of the ilk of you, with medical backgrounds, very quickly said there was a different quality to these calls.

And so because we were unable to get any assistance, it's more or less as though you're on the street with your thumb out, give me a ride, but you keep walking. We started doing the work. So this is an enormous opportunity for a better understanding of what can happen. And I think that this particular woman that we have been working with is probably the most authentic opportunity ever. And I'm so proud that you're doing what you're doing. But I want to keep the facts straight, and that there is a lot of literature that has already reported this in other people. But the politics of this have casted off into accident.

Mark Lebwohl MD: We have a list, thank you. We really should move on because we've got four cases. So let's go now to Mr. ... [inaudible 00:20:00]