

A Worm's Eye View

[Announcer] This program is presented by the Centers for Disease Control and Prevention.

[Sarah Gregory] Hi, I'm Sarah Gregory, and today I'm talking with Ben Taylor, the cover artist for the August 2018 issue of Emerging Infectious Diseases. Welcome, Ben.

[Ben Taylor] Thank you. Hello, Sarah.

[Sarah Gregory] So first, describe the painting as in its final rendition, and then give us a little bit about your background and your life and adventures.

[Ben Taylor] Okay, sure. So, the painting, it depicts my encounter with *Loa loa*, the African eye worm, as it's sometimes called. And yeah, it conveys some of the, what shall we say, shock and awe, actually, of these parasites that I have now. The, yeah, I mean, the adventures that I found myself on when I caught this parasite—I was in the jungles of Gabon, which is in Central Africa, and I was undergoing a rite of passage, an initiation, with a group of people known as the Pygmies. These are particularly a tribe called Babongo. And, yeah, endemic to the area is this parasite, the *Loa loa*.

So, yeah, I've been traveling all my life, really. I was born in Australia, now living in the UK. I was born to parents who enjoyed traveling and working abroad, and even grandparents on both sides were travelers. On one side I had grandparents who were missionaries in Africa. And on the other, my other grandfather was a botanical explorer and a director of a very famous botanical gardens here in England. So, I think it was really in my blood, so to speak. And yeah, brought up in Australia, Nigeria, and then Scotland, and then, finally, England. I've also spent time visiting my father in Kenya and India. So, yeah, I've always traveled quite a lot, and then in my teens and twenties, there were some difficult years, some difficult life events for me. And I think I avoided dealing and processing these things by traveling around the world partying for the best part of a decade. Got into different adventure, adrenalin sports—skydiving, I was obsessed with that for many years—then ended up in London and became a trapeze artist.

And throughout all of that time, I was working as something called an industrial model maker, so I was sort of honing a, I suppose, a craft-based practice that, yeah, an arts-based practice, as well, and I was learning how to use machinery and tools in a workshop. And then I ended up retraining as something called a CGI artist, working with computer software. This was in the field of advertising. I then became a company director and realized that that was not the life for me. So, I ended up quitting, going to Africa to be initiated into this tradition, and I moved out to the wild, wild west of the UK with my lovely wife and started doing my own arts practice, yeah, based on some of the experiences and adventures I've had. And then, I suppose, for the last 10 years, I've been traveling backwards and forwards to both Gabon and South America and other places, studying different spiritual traditions, meditation, and things like that.

[Sarah Gregory] So, to go along with this fascinating and, I must say, horrifying painting, you've had a pretty horrifying experience. So, you got home from these travels and you were not feeling well. You want to describe that period?

[Ben Taylor] Yeah, sure, sure. Well, I mean, initially when I got home, I was feeling fine. One always kind of comes back from those kinds of environments a little bit worse for wear, or I do

anyway. I'd lost a bit of weight, covered in mosquito bites, etc., but no, I felt fine. The first symptoms didn't appear for about six months and I was actually on a, on a meditation retreat at the time. And, in my meditation, I felt a sensation on one side of my forehead, and it was like a little rubber band suddenly snapped inside my head. And, as the day went on, a lump, about two centimeters, appeared where the sensation had been. Then, during the night, another one formed on the other side of my forehead. So, when I looked in the mirror the next morning, I had what appeared to be a set of budding horns. And then these lumps just started coming all over my body and then disappearing a day later, in different places, but especially near my joints, accompanied by various aches and pains. And I later found out these lumps are called Calabar swellings and they're caused by the adult version of this worm. I'll tell you a little bit about the two different stages it inhabits.

But the adult worms, they secrete a toxin which attacks the immune system, and when they stay still for too long in one part of the body, this will cause a reaction and a lump will form. So, often they have to slow down when they pass through the joints of the body, which is why I, sort of, just started getting more lumps there and more aches. I didn't know what was going on at this point. Presented myself to local doctors, but whenever I presented myself, the lumps had gone down. Other symptoms. . . I had fatigue, started feeling very depressed, which isn't really like my persona. I had abscesses started to appear on my legs, which led to hospitalizations. Patches of eczema, small patches went rampant. And then I had several bouts of extreme pain in my eyes. And it would come on very, very quickly, with no warning, and it would feel like the surface, the retina had been badly scratched. So, even with my eye closed, it would still be very painful. And there was a photosensitivity thing going on, as well. I couldn't be in bright lights. And that would last normally about a day and then disappear.

So, again, you know, I went to the opticians at some point, but they found nothing wrong. And, what else? I mean I had my, I had blood tests done by the health system here, and it showed that my eosinophil, or white blood cell count, was skyrocketing. And I think this would, this indicated that my immune system was under attack by something, but I'd had private and health service stool tests, which had come back negative for parasites, basically. But it did show that my gut flora was out of kilter, so I was putting myself on all sorts of dietary restrictions and unusual medical protocols. So, all of this was going on, and it was mystifying my local doctors, mystifying my witch doctor friends in Gabon, and with me getting, I think, used to, I was just starting to become norm—it felt like it was becoming normal to have all these strange things going on. So, on the one hand, I was getting used to it, and on the other hand, I was going completely mad with it.

[Sarah Gregory] So, how does this painting—I think you call it “The Host”—how does this fit into your illness?

[Ben Taylor] Well, it fits in a couple of ways, really, I suppose. It's—now, it's a literal representation, albeit slightly exaggerated—the painting has three little wriggly worms in its eye, whereas I only had the one appear in mine. So, there's that aspect to it, but then there's the, from a psychological viewpoint, I think there's a spiraling pattern within the eye, that leads further and further into the kind of pupil, the dark abyss at the center. And I think that pretty much sums up where my state of mind was or where I was being led at that time. I felt, yeah, it was very dark times, really, before I had the diagnosis, and didn't know what was happening to my body.

[Sarah Gregory] Wasn't there sort of a first rendition of this painting that you kinda did, and put it away?

[Ben Taylor] Well, yes, it did. Before, before I got the diagnosis, I was spending time in studio. I—one of the forms that I've always been attracted to is the circle or sphere, and it's popped up in my artwork numerous times. And I started a new canvas, and again, I felt drawn towards working with circular form. But as the painting progressed, I couldn't find a clear direction to take it in. And I found myself, hour after hour, creating these intricate worm-like squiggles, infilling kind of spiraling patterns within the circle. And the colors that I used, they somehow jarred with me, the piece so overworked, I really didn't like it and I just couldn't bond with it. So, I got very frustrated by that process and put the painting back in a stack of canvases. And, yeah, kind of got on with the next stage of life, which was when the worm appeared and I started going in for all the medical treatments.

[Sarah Gregory] What is the Loa loa parasite and how did you finally realize you had it?

[Ben Taylor] Ah, well, the way I realized I had it was I had another bout of this eye pain. This was just as my wife had gone off for eight weeks traveling, the day after. And this time it lasted a couple of days. It didn't go away really. And I woke up one morning, looked in the mirror, and thought I saw a kind of small lump sticking out of the side of my eye, a kind of yellow, yellow to white lump. And I thought maybe it was some sleep sand or some sleep gunk in my eye. And I went to wipe it away and realized it was actually kind of on the surface, it was a hard lump. And so, yeah, I did what I think most people do in this day and age, the first thing you do is consult Dr. Google. And I remember sort of scrolling down past some images of different things in people's eyes and seeing some pictures of Loa loa worms wriggling in people's eyes. And I remember clearly thinking, "Thank God I haven't got that!" Literally, as I was looking on the computer, my eye started to kind of fibrillate, it started to vibrate, and was a very, very strange sensation. So, I went back to the mirror, I looked in it and the lump on the side had gone, but what there now was was a kind of small horseshoe shape of a kind of raised white welt on my eyeball. And I touched it and it wriggled. And at that point, it kind of appeared and wriggled across the surface of my eye. So, I had no doubt, really, at that point, that, yes, I had a worm in my eye. So, I took myself off to hospital, a local hospital, which wasn't easy, to be honest, because it was, yes, it was a little bit painful with this thing crawling around. And I presented myself to the triage nurse, and this was on a Saturday night, and, you know, I think she looked me up and down and wondered, you know, I obviously didn't smell of alcohol, but perhaps I'd taken some drugs, you know, who knows. So, they were quite dismissive, but then eventually they looked in there, and they found something wriggling. So, yeah, the surgeon was called in and he removed it. Apparently, later on, when I spoke with the kind of specialist on all of this, they said you really shouldn't remove these things, because if it had broken while it was being pulled out, that would have caused some serious problems for my eye.

[Sarah Gregory] Oh dear.

[Ben Taylor] Anyway, I was actually very glad for it to be out. But I, when I eventually got home, sort of thinking, "Thank goodness this worm has got out, has come out of my eye," I then kind of went back to Dr. Google and looked up what Loa loa was all about, and realized that it wasn't about one worm, it's about many worms. So, yeah, when you ask what this parasite is, it's a...it's a parasite that exists in two different forms. It exists microscopically in the blood, and

then, at certain points, it becomes an adult and transforms into a macroscopic worm that can invade. They can be up to eight centimeters long. The one that was pulled out of my eye was three and a half centimeters. And it's delivered by a little fly called a mango fly or a deer fly. And it, in its microscopic form, it burrows through the head of this fly and sticks itself halfway out of its proboscis. This fly is attracted to blood and, yeah, so, I think it must have come to a mosquito bite or something like that. And when it, when the fly bites you, the little larva crawls into the human and begins its kind of next stage of development. So, they're incredibly plucky little things, and you know, this had gone undetected for quite a while. But the real kind of revelation for me, and actually why I'm very grateful to this parasite, is that, while I was receiving treatment, another, two other parasites were discovered—one called strongyloides and another one called hookworm. And I think these had probably been with me for many years, actually, and they hadn't shown up in any of the tests. And it was even after three blood tests that they found them. So, without the Loa loa, kind of, yeah, bringing me under a kind of medical microscope, shall we say, the other two parasites would have continued and the long-term prognosis for having them is not good.

[Sarah Gregory] Ah, so is there treatment for all this? What's the treatment?

[Ben Taylor] The treatment can depend on the level of infestation. So, if someone has very high levels of them, especially microscopically in the blood is actually more dangerous, then chemotherapy is the kind of last resort. So, you know, for the two weeks before I got the blood count, or the, or the infestation count, that was a little bit scary, 'cause I really didn't know what I was up against. As it turns out, I was relatively lucky. I had quite a low count, and so the treatment that they use for those kind of cases is this drug called DEC, which stands for diethylcarbamazine citrate, I believe. But the main danger for the treatment occurs when the parasite's killed off. They can cause toxic overload because they can be in your brain, in the organs, they...all over the body. So, they, the kind of process of killing them off has to be managed very carefully, and they also put me on a high dose of steroids to counteract that. So, yeah, that was the main treatment for the Loa loa, and then the other one, the other two parasites were treated with a couple of doses of a drug called albendazole, I think it is. Yep, that's, that's the treatment. I got off relatively lightly, so I was only in hospital for five days. That's it, really.

[Sarah Gregory] So, you're done with the treatment?

[Ben Taylor] Yes, I'm done with the treatment. I, it took a little while for everything to settle back down. The first, kind of, checkups I had six months after showed very, very slight raising of the eosinophil levels, which, I was, I was assured that I was all clear. What was interesting, though, was, at a certain point, and actually it never really went away, and to this day I still get them. I think I've been left with a kind of psychological glitch where I sometimes feel them moving in my body.

[Sarah Gregory] Oh no!

[Ben Taylor] Yeah, but it's okay. I mean, this was actually, I was warned of this by one of the consultants up in London, during the treatment, that sometimes when people go through these kind of extreme experiences, that they can, yeah, kind of have physical memories of it. So, I've since been tested twice since then. My eosinophil count is absolutely normal, my immune

system's not under attack by anything, so I feel quite happy in the knowledge that this is just a little psychological glitch that's been left.

[Sarah Gregory] Well, hopefully it will cease at some point. So, when did it occur to you that the painting that you had begun and put away was a little bit prescient?

[Ben Taylor] Well, it wasn't until I was convalescing after the treatment that I returned to my studio again. And at a certain point, I pulled out the old painting to look at it, and it had been put away upside down. So, when I viewed it from a different angle, it suddenly appeared to me as an eye. And when I realized the kind of significance of this painting that had the look of an eye and it was comprised of layers of worm-like patterning, umm yeah, things kind of started to fall a little bit into place, because it hadn't really been a style that I'd been drawn to or worked with prior to that. But, yes, I feel a little bit obsessed with patterns and textures nowadays. So, I suppose it was about then. And then, yeah, so, at that point, I restarted the painting and I turned it into the piece as it is now, kind of adding the eyelids, the other colors, and the worms themselves.

[Sarah Gregory] Well, it is certainly a very eye-catching and stunning piece.

[Ben Taylor] Excuse the pun.

[Sarah Gregory] It's gotten a fair amount of press, and even in some major newspapers. And what has, what's that been like for you and what are you, what are people saying about the painting?

[Ben Taylor] Yeah, it has got quite a lot of coverage, and I'd like to thank Byron for kicking that all off by asking me if he could use the image as a cover.

[Sarah Gregory] Let me interrupt here to say that "Byron" is Byron Breedlove, the managing editor of the EID journal.

[Ben Taylor] And a very nice chap as well. But yeah, you know, don't worry, I'm not having to fend off the paparazzi just yet. It hasn't quite got to that stage. So, what have they been saying about it? Well, I think the majority of the articles and the subsequent comments that appeared, have probably been emphasizing the "ick!" aspects of this quite a lot.

[Sarah Gregory] Yeah.

[Ben Taylor] But then there's been a few articles that, yeah, have looked a bit deeper into such things as how a parasitic infection can influence or, in some of nature's examples, completely control its host. And that's been the aspect that's been really kind of interesting for me. And I suppose one of the other by-products is that, just along the way, I have been contacted by many other people, actually, who have been off traveling to far-flung places, and are experiencing very strange symptoms and, you know, have not been able to ascribe a reason to it. So, I think, you know, one of the things that I've realized from this is that various different parasitic infections, you know, one of the by-products of us traveling so much in the modern age, is that we are being exposed, you know, in countries like the UK or America or places that aren't used to these kind of parasites, we're suddenly starting to have to learn about them.

[Sarah Gregory] So, you've done, sorta been, your experience is helping other people.

[Ben Taylor] Yes, it is. I suppose it is, to a degree. So, the, for me, the kind of process of figuring out whether you have a parasitic infection, most people seem to presume that, if they have something parasitic going on, that it's in their gut, so, you know, that's not always the case. The other thing is most remedies, etc. will concentrate on stuff that works through the, yeah, through the gut. For me now, my understanding is, really, the best thing is to find out if your immune system is under attack or not. And that way you have then some proof, to yourself, that something is going on. So, a lot of this time, I think when you have just weird and wonderful symptoms, you present to a doctor, and they say "Well, there's nothing wrong with you." Then you're, you're, yeah, going to become quite, kind of, unwilling to kind of look into it yourself. You start trusting that the doctors know what they're saying and that you're just going mad. So, yeah, I suppose it has helped other people, as well. And it's, it's given me a nice painting and some nice publicity as an artist out of it, as well. So, no complaints really. But I'm not so keen to return to the same place again, if I'm honest with you. No.

[Sarah Gregory] So, you said you lived in the forest. What does that mean—really a forest, like a little cabin?

[Ben Taylor] Yes! Well, funnily enough, for the last 10 years, we were living in a little cabin in the woods. We were living in the site of an old abandoned mine. So, yes, we were living quite an adventurous lifestyle, I suppose. There's not that much forest in the British Isles, but we happen to live in the west of the country, in a national park called Dartmoor, and it's quite a wild place itself. So, it does, I suppose it promotes adventurous living. Yeah, and we have just moved a little bit further into the wild, into another forest. This time we're kind of on the edge of civilization. We do have a few neighbors around us, so trying to get used to coming back to civilization now.

[Sarah Gregory] So, you're not really giving up the adventurous life, despite your experience with the Loa loa eye worm?

[Ben Taylor] No, absolutely not. You know, I've kind of been asked that kind of thing before, you know, "Does this kind of thing put you off an adventurous life?" You know, like I say, specifically, that particular location, yes, I wouldn't be keen to return there again. But, you know, I, my, I suppose my view is that, you know, a lot of our society tries to sort of protect us from danger. You know, we live in a very kind of health- and safety-conscious society. All of these kind of things try to wrap us up in cotton wool. And, you know, I think danger, or the potential of danger, is present or, you know, yeah, the potential of danger is present in our lives at all times. And, you know, I really wouldn't want to focus on that. I prefer focusing on living my life as fully as possible. And yeah, I think when, when you, if you want to really connect to nature, as well, then you're going to expose yourself to creepy-crawlies. So, they don't scare me nearly as much as some other things in this world nowadays.

[Sarah Gregory] Yeah, well you have certainly lived through a very interesting experience and we have the painting to enjoy because of it. Thank you, thank you very much for talking to us, Ben. Listeners can see the painting and read the cover essay, "A Worm's Eye View," online at cdc.gov/eid. I'm Sarah Gregory for *Emerging Infectious Diseases*.

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