

**04:00:00**      **DR. KIMURA:** All right. So Julia. Um, let's see. You are thirteen and a half, and Dr. Handler is your pediatrician, and you're here because of headaches, blurry vision.

All right. So, I've had a chance to review some of the lab work that Dr. Handler had sent, and I spoke with him a little bit about, you, now, what's been going on. But maybe you can tell me in your words what's going on, and you know, also you too, Julia. Okay? So tell me when this all started and how, and all that.

**04:00:50**      **MOM:** The first symptom she had was this rash on the back of her neck.

**DR. KIMURA:** Okay. When was that?

**MOM:** And uh, middle of September.

**DR. KIMURA:** Uh huh. Okay. Okay.

**04:01:04**

**MOM:** And that was followed by headache, nausea, um, little bit of vomiting, but it was more like retching, it wasn't really the whole contents of her stomach.

**DR. KIMURA:** Mm hm.

**MOM:** It's just kind of bile and...

**DR. KIMURA:** So just going back to the rash for a minute. Um, what did the rash look like, and-

**JULIA:** Well I, it was kind of like, not really bumpy, it stayed in the same spot.

**DR. KIMURA:** Mm hm.

**JULIA:** It just kind of raised and dropped, and the color changed a little.

**DR. KIMURA:** What was the color?

**JULIA:** It was like red, and sometimes if it would get better it turned like purplish. And like.

**DR. KIMURA:** And um, so were they little bumps, or was it a big blotch, or what was it?

**JULIA:** More like a blotch.

**MOM:** It was big and blotchy and irregular.

**04:01:57**      **DR. KIMURA:** Uh huh.

**MOM:** And raised, but there was no head or pus or anything like that, it never oozed, it never really changed location or size or shape, just that the color when it flared up it would get more red. And then it would kind of calm down and get more purplish brown.

**04:02:16** **DR. KIMURA:** And it only stayed in this... just....

**MOM:** ...right in the back of her neck.

**DR. KIMURA:** Okay.

**MOM:** Never anywhere else on her body.

**DR. KIMURA:** Was it on her scalp, or...

**MOM:** ... above the hair line, a little bit.

**DR. KIMURA:** And was it itchy or painful?

**JULIA:** Um, it, it itched and it burned a little. Like not, it wasn't like really intense burning, and it itched a lot more than it burned.

**MOM:** Mm hm.

**04:02:40** **DR. KIMURA:** And um, was it on um, in the middle of your neck, or was it...

**MOM:** All the way across. It went all the way across the neck, and up into the hairline.

**DR. KIMURA:** And how long did it last?

**MOM:** Over a month. Uh...

**DR. KIMURA:** Okay.

**MOM:** It's only been in the past couple of weeks that we can really say it's gone.

**DR. KIMURA:** Okay.

**04:03:03** **JULIA:** Is it really gone though, cause I can't see it. [LAUGHTER]

**MOM:** Pretty much.

**DR. KIMURA:** And um, I see that she had a biopsy of the rash.

**MOM:** Yes.

**DR. KIMURA:** And that was, what period of time during the...?

**MOM:** Uh, the biopsy was done October 15<sup>th</sup>? So by then she had already had the rash for a month.

**04:03:20**      **DR. KIMURA:** Okay.

**MOM:** And it had sort of gotten a little bit better and then flared up and gotten much worse again, and...

**DR. KIMURA:** Mm hm.

**MOM:** ...she ended up being hospitalized, and the dermatologist came to the hospital and saw her there,

**DR. KIMURA:** Oh, so...

**MOM:** ...and as soon as she was discharged we went to the dermatologist's office and they did the biopsy.

**04:03:38**      **DR. KIMURA:** So she developed the rash and then, how, how much later did she develop the other symptoms, the headache, the nausea...?

**MOM:** Two weeks?

**JULIA:** About two weeks, I guess. Like a week and a half, kind of.

**DR. KIMURA:** So it wasn't right away.

**JULIA:** No.

**04:03:52**      **MOM:** No.

**DR. KIMURA:** And she didn't have any fever?

**MOM:** No.

**DR. KIMURA:** Okay.

**JULIA:** Except for in the hospital.

**DR. KIMURA:** Okay. So no fever initially...

**MOM:** No.

**DR. KIMURA:** ...when the rash started, or when the other symptoms started. So she had headaches, nausea, and so what did you do at that point?

**04:04:47**      **MOM:** Uh, well, initially, when we saw the rash, I thought it was an allergic reaction, so I treated it with, you know, Benadryl and cortisone cream.

**DR. KIMURA:** Mm hm.

**MOM:** And then when she got the uh, headache, stomach ache, nausea symptoms, I thought okay, it's a virus, so it'll just run its course.

**DR. KIMURA:** Mm hm.

**04:04:25** **MOM:** But then another week and a half went by, and she still wasn't any better, so then I took her to the pediatrician. And they ordered blood tests, and they did a, uh, urine test, and they found that she had a urinary tract infection.

**DR. KIMURA:** Mm hm.

**MOM:** Uh, even though the initial urinalysis was normal, but the overnight culture came back positive for a urinary tract infection.

**DR. KIMURA:** Mm hm.

**04:04:51** **MOM:** So they started her on Bactrim for that, and after a few days she apparently developed a reaction to the Bactrim.

**DR. KIMURA:** Okay.

**MOM:** She broke out in the second rash, and little spots all over her body.

**JULIA:** Which are gone now.

**DR. KIMURA:** Okay. So that was a different kind of a rash.

**MOM:** Yes.

**04:05:10** **JULIA:** Yes.

**DR. KIMURA:** And it was itchy and really looked like hives, or...?

**JULIA:** It was itchy, and it was like, it wasn't really bumpy, it was just like red, kind of, like...

**DR. KIMURA:** Like welts, kind of?

**MOM:** No. Small little red spots.

**JULIA:** Small...

**MOM:** All over her stomach, arms, legs.

**04:05:27** **DR. KIMURA:** Okay.

**JULIA:** They weren't really like sticking out of my skin, they were just like dots.

**MOM:** Not very raised.

**DR. KIMURA:** Okay. And then, um, so that was treated with Benadryl, I assume?

**JULIA:** Mm hm.

**MOM:** Yes.

**DR. KIMURA:** And it went away after how long?

**04:05:39** **MOM:** Um, not even a week, I think it was.

**JULIA:** It was like five days.

**DR. KIMURA:** Okay.

**JULIA:** Yeah.

**MOM:** That was when she was hospitalized.

**DR. KIMURA:** Uh huh. When was she hospitalized, uh...?

**MOM:** Well, we went to the emergency room on October 12<sup>th</sup>.

**DR. KIMURA:** And that was after she developed the reaction, or...?

**04:05:57** **MOM:** Um... At that time we didn't realize that she was having a reaction to the Bactrim. All we knew was that the, the rash on the back of her neck had flared up again, and gotten very red, and the headaches and the retching were really bad, and she had also, by this point, developed this blurry vision. And she was having a lot of difficulty reading and doing her homework.

**DR. KIMURA:** Mm hm.

**04:06:19** **JULIA:** I was very tired, too. Then.

**MOM:** Mm hm. She was...

**JULIA:** ... the whole time.

**DR. KIMURA:** Were you, um, going to school this entire time, also?

**JULIA:** Not the entire time.

**MOM:** Well, up to that point.

**DR. KIMURA:** Yeah.

**JULIA:** Yeah, up to that point.

**MOM:** Up to that point. Yeah.

**04:06:33**      **DR. KIMURA:** Okay. So, um, so this was after she had started the Bactrim, that she was hospitalized?

**MOM:** Yes.

**DR. KIMURA:** Okay. So that was before she developed the reaction, or...?

**MOM:** Um, yes, well on, on Sunday, the 12<sup>th</sup>, I took her to the emergency room, I – I was starting to wonder if maybe she had had a concussion on the soccer field, cause she plays on two of the soccer teams.

**04:06:59**      **DR. KIMURA:** Mm hm.

**MOM:** And maybe we never knew it. But the headache and the blurry vision were really starting to frighten us, so, she was in the emergency room for about five hours that day, and they did the CAT scan, and more blood work, and then they sent her home, and the next morning, which was Columbus Day, Monday the 13<sup>th</sup>, we brought her back to the pediatrician's office, and she was deteriorating before our eyes, got the point where she couldn't even hold up her head.

**04:07:28**      **DR. KIMURA:** Mm.

**MOM:** And they decided to admit her, right there, so we went back to the hospital, and they put her on IV fluids, and uh, that, that was when the Bactrim rash started popping out, when we were there in the pediatrician's office, Monday morning. So they started her on the Benadryl, IV, Benadryl and fluids.

**04:07:51**      **DR. KIMURA:** And what did they do for her in the hospital?

**MOM:** Um, more testing, she was seen by an infectious disease doctor at that point, uh...

**JULIA:** (UNINTEL)

**MOM:** No, chest X-ray. She had the chest X-ray, they did a strep test...

**JULIA:** They did a CAT scan, though, before.

**MOM:** The day before. Sunday was the CAT scan, Monday was the chest X-ray.

**04:08:17**      **DR. KIMURA:** So the CAT scan was normal, I see the chest X-ray was normal.

**MOM:** Chest X-ray was normal.

**DR. KIMURA:** And ...

**MOM:** Strep test was normal.

**DR. KIMURA:** Mm hm.

**MOM:** They did more blood work.

**DR. KIMURA:** But she was still continuing to have the blurry vision and headaches and all that.

**04:08:30** **MOM:** And the very angry red rash, and many doctors came, and looked at the rash, and they all said wow, that's interesting, I don't know what that is. I've never seen that before.

**DR. KIMURA:** (LAUGHS) Okay. And uh, the dermatologist also saw it, and...

**MOM:** And the next day, she stayed overnight in the hospital.

**DR. KIMURA:** Uh huh.

**04:08:47** **MOM:** And she was on IV fluids for 24 hours, and the next morning the dermatologist stopped by, and said, you know, when you get out, you know, come to my office, and I'll do the biopsy right away.

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**DR. KIMURA:** Okay.

**MOM:** So she took the biopsy, they mailed it off, it took two weeks to get the result back. It said insect bite.

**DR. KIMURA:** Okay. (LAUGHS) So not too helpful. Um, and did she have an MRI when she was in the hospital?

**MOM:** No.

**DR. KIMURA:** Okay. Did she –

**04:09:17** **MOM:** We went to a neurologist... After she was discharged from the hospital on Tuesday afternoon the 14<sup>th</sup>, we had to set up appointments with the dermatologist, the ophthalmologist, the neurologist, and then we had to go back to the hospital for more blood work.

**DR. KIMURA:** Okay.

**04:09:35** **MOM:** And the neurologist said, this was Dr. Warren, in Morristown.

**DR. KIMURA:** Mm hm.

**MOM:** He said he didn't want to start ordering MRIs and spinal taps unless he had an idea what he was looking for. Otherwise it was a needle in a haystack. He said there are different types of MRIs and he has to know what he's looking for.

**DR. KIMURA:** Okay.

**MOM:** So HE suggested that we come to see you. And Dr. Handler seconded that recommendation.

**04:09:57** **DR. KIMURA:** And the dermatologist basically just did the biopsy, but he didn't have any—

**MOM:** ... gave us some creams and things, just to help with the itching.

**DR. KIMURA:** Uh huh. And did it, what kind of creams?

**MOM:** Oh, I don't know... (LAUGHS)

**DR. KIMURA:** (LAUGHS)

**MOM:** I'm sorry.

**04:10:16** **DR. KIMURA:** Um, so that, did that help?

**MOM:** I think so.

**JULIA:** Yeah.

**DR. KIMURA:** Yeah?

**JULIA:** Stopped all the itching...

**MOM:** You only used them for a few days, and...

**JULIA:** Yeah. And it started like getting better, so.

**DR. KIMURA:** Okay. So it's hard to tell what it was, whether it was just getting better by itself.

**04:10:34** **MOM:** Well, part was – well, the second rash, the Bactrim I think just had to get in her system—

**DR. KIMURA:** Right.

**MOM:** And then, that one went away.

**DR. KIMURA:** So, and the ophthalmologist I saw her note, that was Dr. Chung, right?

**MOM:** Yes.

**04:10:47** **DR. KIMURA:** And she didn't find anything on her...



**MOM:** She said the eyes themselves are fine, there's nothing wrong with the eyes themselves. And Julia did the vision test, I think it was 20/20 in one eye and 20/30 in the other, and she can do it, but you can see that she's really straining and squinting and after she does it her head hurts a lot worse.

**DR. KIMURA:** Mm hm. Okay. So, since she was discharged, what's, what's happened?

**04:11:11** **MOM:** She stayed out of school for a week.

**DR. KIMURA:** Okay.

**MOM:** Then she went back to school. The school has made some accommodations for her, they've been very nice, they're letting her listen to Books on Tape, then they're moving her closer to the board, and they excused her from some of the computer work because staring at the computer screen and trying to read the words is very difficult for her.

**DR. KIMURA:** Mm hm.

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**MOM:** Then she went back, Dr. Handler said she wanted her back on all her regular activities.

**DR. KIMURA:** Mm hm.

**04:11:39** **MOM:** And we did do one more set of blood work. And her, her, looks like her white blood cell count was finally coming back up.

**DR. KIMURA:** Uh huh.

**MOM:** So she seems to be getting better, but she still has the headache which is continuous, never goes away. And gets worse when her eyes are straining. We've actually, she's wearing magnifying glasses now to help her read.

**DR. KIMURA:** Mm. Okay.

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**04:12:08** **DR. KIMURA:** So tell me exactly what you, what you see when you're looking straight ahead.

**JULIA:** Like, just, I can see everything normal, until I try to read, then I just kind of like, I can make out the words, and it's not like it's double vision, but it's like, kind of, just a little blurry.

**DR. KIMURA:** Okay. So when you s--, when you look at me, I don't look blurry at all?

**JULIA:** No. // And when I read // like bigger print it doesn't hurt at all.

**DR. KIMURA:** Used to hurt your eyes?

**JULIA:** Well, it would hurt my head.

**DR. KIMURA:** I see. And do you think that your head, headache is, is, even though it's constant, is that improving?

**JULIA:** It's kind of hard to tell, since it is constant. But it's getting better, I guess.

**04:12:58** **DR. KIMURA:** Is it more tolerable?

**JULIA:** Yeah.

**MOM:** You said you learned to ignore it.

**JULIA:** Yeah, there's, there's points where I can ignore it.

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**DR. KIMURA:** Um, and are you having any trouble sleeping?

**JULIA:** Um, only if the headache keeps me up.

**04:13:16** **DR. KIMURA:** Okay.

**JULIA:** But not usually.

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**DR. KIMURA:** Um, have you ever had depression or anxiety?

**JULIA:** Mmmm.... Anxiety meaning stress?

**04:13:29** **DR. KIMURA:** Well, yeah, whatever you have when you...

**JULIA:** Well, anxiety, yeah, just like school and...

**DR. KIMURA:** Uh huh.

**JULIA:** Doing all the things that teenagers do. (LAUGHS)

**DR. KIMURA:** (LAUGHS) Um, but you don't think anything more than normal.

**JULIA:** Mmmm, no.

**04:13:44** **DR. KIMURA:** And you feel, you don't feel depressed or anxious now.

**JULIA:** No.

**DR. KIMURA:** Okay. // And you're doing okay in school now?

**JULIA:** Yeah.

**DR. KIMURA:** Okay.

**JULIA:** B, A averages.

**04:13:55** **DR. KIMURA:** Uh huh. Um, and you don't normally miss a lot of school?

**MOM:** No.

**DR. KIMURA:** Okay. Okay, both parents live at home, no other issues at home to speak of, and she has no other problems with her health that you know of?

**MOM:** No.

**DR. KIMURA:** Okay.

**MOM:** She's been a pretty healthy specimen up to now.

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**DR. KIMURA:** Okay. Good. Okay. All right. Um, I think we're gonna examine you now, so um, we're gonna go to the room next door. I'm gonna give you something to change into. // And then we'll come back. Okay? Right.

**JULIA:** Okay.

//

**FOLLOWING THE EXAM]**

**04:14:32** **DR. KIMURA:** So I think it may be worth repeating a few tests and maybe looking at a few extra things. Um, I have to say that, you know, in general, I think that uh, from what you've told me, has the flavor of some type of, you know, infectious process. Um, because it sort of started suddenly, um, you know, with a rash, and, and then all the symptoms have been kind of gradually, very gradually but definitely, getting better. So uh, without any really specific treatment.

**04:15:07** So, I think that that is most likely what this is going to turn out to be. Now, what kind of infection per se, is, you know, is maybe a different, um, question that we should ask, and we may not be able to identify exactly what kind of infection it was, ultimately, but if it all gets better and goes away, then, you know, it doesn't really matter in the end. Obviously, if it doesn't get better, and it doesn't go away completely –

**04:15:36**        **MOM:** That's it. She's definitely feeling better than she was a few weeks ago, but she's still left with this constant headache and blurry vision and difficulty reading.

**DR. KIMURA:** Yeah. Yep. So we need to sort of get to the bottom of it. Um, I will, I'm gonna speak with um, Dr. Warren, about doing some more testing, um, you know, at least I would think an MRI would be in order, if not further testing. Um, and maybe even a spinal tap to see whether the pressures inside her, you know, her um, uh, central nervous system are elevated.

**04:16:13**        So um, so those kinds of things we need to do, we also need to see whether there's evidence of some infection in her, um, you know, around her, her brain or spinal cord that are causing some of these symptoms. You know, there are many different types of viruses, for example, that could cause inflammation, you know, around your brain that could cause headaches and some of these similar symptoms. So –

**04:16:35**        **MOM:** And how would we test for that?

**DR. KIMURA:** Well, um, that's what we need to figure out, whether it's worth doing a spinal tap at this point, um, or whether we just start with the MRI and sort of take it from there.

**04:16:47**        But I think if her symptoms persist, I think we don't really have a, a choice in terms of, you know, doing more testing. Um, in terms of um, autoimmune problems, I, you know, um, uh, I – I doubt that this is what this going to turn out to be, because again, she seems to be getting better without any specific treatment, and all the different autoimmune diseases that would cause this sort of um, problem, wouldn't get better spontaneously.

**04:17:18**        But, you know, we'll keep a close eye on things to make sure that they don't relapse and no uh, there are no other indications that there is some sort of systemic problem going on. Um, so we'll, you know, continue to be in touch by phone, we'll do some blood tests to look at um, some diseases that we can detect, uh, bi-blood tests to make sure that she doesn't have any of those, like lupus for example. I think the doctors are also concerned about the possibility of something like avasculitis, which is an inflammation the blood vessels in your brain.

**04:17:51** But um, again, I would think that the, you know, these um, that you wouldn't be improving without any treatment, um, if that were the case. So I – I doubt that that's what it is, and those are, that's good. (LAUGHS) Um, and I know that she did have Lyme testing, which was negative, but I'm just gonna repeat it one more time.

**04:18:12** **MOM:** I think we should, yeah.

**DR. KIMURA:** Because uh, you know, Lyme is certainly something that can cause um, you know, neurological symptoms and headaches, and can cause a rash, although the rash doesn't sound like it was very typical –

**MOM:** No.

**DR. KIMURA:** But it was so localized I just sort of wonder whether it was sort of an atypical rash –

**04:18:31** **MOM:** And the first test for Lyme disease was in that indeterminate zone, you know, not really positive or negative.

**DR. KIMURA:** Uh huh.

**MOM:** So, and we've spoken to people that have said they needed three and four Lyme tests before they got a positive result, so.

**DR. KIMURA:** Right.

**04:18:42** **MOM:** I think it makes sense to do that again.

**DR. KIMURA:** Yeah.

**MOM:** What about something like West Nile virus?

**DR. KIMURA:** Um, well, I, West Nile virus, um, I – yes, can certainly cause neurological symptoms, um, but I'm, you know, I know that you saw an infectious disease specialist, um, who –

**MOM:** Dr. Bayard.

**04:19:03** **DR. KIMURA:** Right. And she did not think that this was um, anything infectious.

**MOM:** Um... I don't think she could really tell, I mean, she, you know, she ordered things like the chest X-ray and the um, strep test, and she ordered this microplasma test which for some reason didn't get done, but then it was done on October 22<sup>nd</sup>.

**DR. KIMURA:** Mm hm.

**04:19:26** **MOM:** And that also had this, um, result that said she ha – it was positive for her antibodies that she had had in the past, and the Epstein-Barr virus also had the same results that she had had in the recent past.

**DR. KIMURA:** Mm hm.

**MOM:** I don't know if there's any conclusions that can be drawn from those two.

**04:19:45** **DR. KIMURA:** No, I mean, you know, it doesn't look like uh, you know, they were, um, just judging from these blood tests, uh, that they were the cause of the um, illness. So um, you know, I don't think that that's worth pursuing. But um, I can certainly speak to, um, you know, our infectious disease people to see if there's anything –

**MOM:** Dr. Taylor suggested that.

**DR. KIMURA:** Uh huh. Okay. So um, let's start with these blood tests first, and I'll speak with Dr. Warren about doing the um, at least the imaging tests, and um, and then we'll just decide whether it's worth your getting um, another opinion with one of our infectious disease people. And um, we'll see where things are. Okay?

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**(OUTSIDE AT FRONT DESK)**

**04:20:29** **DR. KIMURA:** So um, you should give us a call maybe um, actually I'm gonna be away, uh, actually for the next ten days or so.

**04:20:36** But I'll be back um, like, my partners will be around, so if there are any major issues they will call you with the blood test results, but um, you want to give me a call um, you know, the week after next, towards the end of the week, I'll have the blood test results back.

And you can always, also speak with Doreen if you need to. Okay?

**MOM:** Okay.

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**04:20:56**      **MOM:** And should I follow up with Dr. Warren?

**DR. KIMURA:** Um, yes, I would give him a call, I'll try to give him a call, obviously before I go away, um, and then if you haven't heard from him by the end of the week, why don't you give him a call. Okay?

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**04:21:11**      **MOM:** And the, um, looks like you ordered a lot of blood tests.

**DR. KIMURA:** Yes.

**MOM:** What are they? Some of these look familiar.

**DR. KIMURA:** Well, I'm gonna check the blood count again, we'll check the sed rates, um, and, which is a mark of inflammation, um, some, you know, levels of bl-- of kidney and liver function, muscle, um, and then a lot of these tests are looking at um, blood tests to look for autoimmune diseases.

**04:21:34**      **MOM:** Okay.

**DR. KIMURA:** And Lyme-Titer we're going to do, Eurychia (?) blood test, which is another tick-borne infection, looking at urine, the immune system, things like that.

**04:21:44**      **MOM:** So they're going to need a urine sample.

**DR. KIMURA:** Yeah. Okay?

//      **MOM:** Okay. Thank you very much for your help.

**DR. KIMURA:** Very nice to meet you. Okay. Bye bye.

**JULIA:** Bye.

**DR. KIMURA:** Bye. Take care. (LAUGHS)