#### Interview with Laika

This interview was conducted on July 11, 2022. The person being interviewed requested that I use their Reddit name instead of a pseudonym. <a href="mailto:u/shutuplaika">u/shutuplaika</a> is a female in her mid-twenties. She is single and does not have children. Laika has Stickler syndrome.

### What is Stickler syndrome?

It's a genetic disorder that can cause serious vision, hearing and joint problems. Also known as hereditary progressive arthro-ophthalmopathy, Stickler syndrome is usually diagnosed during infancy or childhood. Children with Sticklers often have distinctive facial features — prominent eyes, a small nose with a scooped-out facial appearance and a receding chin. They are often born with an opening in the roof of the mouth (cleft palate).

Common symptoms are eye problems, hearing difficulties, and bone and joint abnormalities. Stickler's is caused by mutations in certain genes involved in the formation of collagen — one of the building blocks of many types of connective tissues. If a parent has Stickler syndrome, there is a 50% chance of any children developing the condition. There is no cure for Stickler syndrome. Learn more at Mayo Clinic

# 1. What is your disability called?

Laika: Stickler Syndrome! It's a spectrum, like many disabilities, so it affects folks in different ways. Me personally, I am mainly affected by my visual impairment, moderate mobility issues, and I can be hard of hearing from time to time, among other things.

2. Have you found any GWA content that includes your disability?

Laika: Nothing specifically. I think I've seen a small handful of blind listener audios, but blindness is a spectrum so it wasn't entirely relatable.

- 3. What type of content are you looking for?
  - A) Interabled the speaker is not disabled, the listener has your disability
  - B) Interabled the speaker has your disability, the listener is not disabled
  - C) Both the speaker and the listener have your disability
  - D) I do not want GWA content about my disability

# E) Other (please explain)

Laika: A and C mainly, but some B mixed in there would be good too! I'd like to make this type of content but I struggle to write anything as I feel it can hit too close to home and haven't come across any scripts that I could see myself performing, as of yet.

- 4. If you are comfortable sharing, what type of NSFW content do you want to find on GWA?
  - A) Kinky sex, vanilla sex, or both?
  - B) What gender tags are you looking for? M4F, F4F, etc.
  - C) What romantic pairings are you looking for? Dating, married, strangers, Dom/sub, etc.
  - D) What sex acts are you looking for? Oral sex, vaginal sex, anal sex, masturbation, etc.
  - E) Are you looking for more content that includes sex toys?
  - F) What kinks and fetishes are you looking for, if any?
  - G) Other (please explain)

Laika: I'd love to see more M4F content, personally. I definitely have a preference for more kinky sex (e.g. bondage/shibari, light degradation,

light impact play, breath play, edging/denial, etc) but more vanilla is definitely good here and there too.

5. Do you refer to your disability by a shortened or different word? For example, many paraplegics call themselves "para", e.g. "I'm John, I'm a para."

Laika: For the most part I refer to myself as blind/visually impaired, (as it's the one that affects me the most!) Most folks don't really know what Stickler syndrome is, so it's much easier to narrow it down to the visual impairment. I do sometimes say Sticklers but that's few and far between.

6. Are there any online resources for learning about your disability, including having sex with your disability, that you recommend for writers?

Laika: For general information about Sticklers:

- RareDiseases.org Sticklers
- Stickler.org.uk about Sticklers

• For information about having sex...nothing that I'm aware of.

7. If sex for you is different or more difficult than for non-disabled people, why is that? Are there things a new partner might not understand about you at first when it comes to sex?

Laika: I would think it's more different than difficult. Touch and sound are better cues than anything visual for me personally, and while I'm sure touch is usually a given, audio cues aren't often thought about as much. (Probably why I enjoy audio porn much more than anything visual!)

8. Do any sex aids exist to help people with your disability?

Laika: Not that I'm aware of!

- 9. People google very specific questions about disabled people, like:
  - "Can paralyzed men get erections?"
  - "Can paralyzed women get wet?"

"Can autistics feel love?"

The question is, with regards to romance and sex, do people make assumptions about what your life is like and what you can and cannot do in bed?

Laika: The questions I get the most relate to my visual impairment, as the other two impairments I have aren't very obvious. I often get the "how many fingers am I holding up?" question or similar, and it is definitely wearing thin.

Another one I get that's aimed towards my relationships (romantic, platonic, family, etc) is "but how do you know what they look like?" For one, looks aren't everything, you know? And two, I still have some vision left! Blindness is a spectrum. Only a small percent of folks have no vision at all. Folks like to assume things that of course aren't true, like:

- I can't cook. (I can't but that's not because of my visual impairment.)
- I can't read. (I can! It used to be my favourite hobby.)
- I can't watch movies/television, etc. (I can, I just don't watch a
  whole lot of it because it's not to my interests!)
- And so on and so forth. I'm a normal person! My eyes, ears and joints just don't work as well as yours.

10. What should writers include in order to describe your disability accurately? What is the best way to describe a person like you, in a porn script, ensuring that your disability is **not erased and** the script **is for** people with your disability?

#### Laika:

- A) For visual impairment: more sound cues! Letting the listener know what you're up to, where you're going, how you're handling the listener and things like that. Sometimes it can be hard to visualize what you're doing if we don't have any visual or audio cues (without reading the script of course, but that spoils the fun sometimes!).
- B) For hard of hearing: for me personally, I struggle from time to time with whispers but my hearing impairment comes and goes so it's not a massive problem for me overall. (But that's not to say it's the same for everyone with a hearing impairment!)
- C) For mobility issues: this one is a tricky one. This is often where a lot of the comfort audios come in and so very few kinky audios appear. I suppose just more check-ins and making sure the listener is comfortable, but this isn't an exhaustive description by any means.

D) And also do your research! Check some resources, watch some videos if you can, ask folks who have the disability you're making content about. Most of the time, we're happy to answer anything within reason!

11. What should writers avoid when writing about your disability?

Laika: Making the person with the visual impairment seem like they are helpless or need to depend on someone constantly! Often, we're super independent and prefer it that way. Others prefer some help here and there, and that's okay too! It's a spectrum and folks generally forget that.

Mobility issues can have good days and bad days too. Sometimes I'll be able to walk a little longer and other days I can't get much further than somewhere within my home. That doesn't mean I can't want something a little spicy, even on the bad days!

12. Tagging is how people find content. For example, I'd tag paraplegia content like this:

[SCI] [paraplegia] [wheelchair] [disabled listener] [interabled relationship]

What tags would you choose for content about your disability?

Laika: [Visually Impaired] [Blind] [VI] and any mobility aids such as [Guide Cane] [Guide Dog] [Cane] [Crutches] etc (but not every visually impaired person or person with mobility issues uses these due to need/cost etc so it's a good thing to keep in mind)

- 13. Regarding "person-first language" and "identity-first language", there is a big push in the medical community and schools, and from parents of disabled people, to avoid saying the word "disabled". For example, they tell us to say "he's a man with paralysis' or "she's a woman with autism". Yet many disabled people say that they do not like this and get annoyed that people treat "disabled" like it's a bad word. The question is, if we write content for your disability, it needs to be tagged so you can find it. What type of tagging do you prefer?
  - A) Person-first, [person with a disability] [person with paralysis]
  - B) Identity-first, [disabled listener] [paralyzed listener]

Laika: I 100% prefer identity first. It normalizes being disabled and makes it less of a "bad word", in my opinion.

14. A common piece of advice in articles about writing for disabled people is, "Ask disabled people what they want, then write that". That leads to a different problem: how does a writer meet disabled people to ask them? Are there any online communities you recommend that welcome questions from non-disabled people?

Laika: I'm not sure about any forums or websites personally but I know a lot of communities are active on other social media such as Twitter.

Usually, folks are happy to answer questions (within reason!) and it helps with destigmatization around sex and disabilities.

15. Please choose a pseudonym to protect your privacy. What shall I call you? (You can use your Reddit name if you wish.)

Laika: You can use my Reddit name! u/shutuplaika

16. If you want me to include your age (or age range), gender, relationship status, and whether or not you are a parent, provide that information here. Example: 40s, male, married, has kids

Laika: Mid 20s, female, single, no kids

17. Do you have other thoughts you would like to share about this?

Laika: Absolutely appreciate you putting this together! It's super interesting to read about other folks experiences, and hopefully eventually see someone with a disability like mine!