Why I Haven’t Done a Fibromyalgia Clinical Trial

by SARAH BORIEN

Why I’m Nervous About Clinical Trials

I’ve had fibromyalgia for more than seven years, and in that time I’ve tried a variety of ways to help and heal my fibromyalgia pain. And sure, I’ve had some successes along the way, but nothing has ever worked in the way it claims to — and I certainly don’t believe in the ads that offer me a cure. I guess you could say that when it comes to my health, I’m a little skeptical.

So when NewLifeOutlook asked me why I had never been part of a clinical trial, it got me thinking...

Lack of Information

If I’m really honest, I don’t know a lot about clinical trials. I’ve always assumed that if there a trial going on that I was suitable for, my GP would let me know.

But even as I type those words, I know how unlikely that is. My GP barely helps when I’m sat in the same room, never mind giving me a call to suggest something that could be useful.

But let’s be fair, I can’t just blame my GP. It’s not like I’ve gone to him to say, “Look at this amazing trial I’ve just discovered.” He hasn’t done his bit, I haven’t done mine, and as a result nothing has happened.

Risks

We all make judgements about things we don’t understand. Sometimes we love things for no reason other than the gut feeling of adoration, and sometimes that same gut feeling fuels anger or hatred. When it comes to clinical trials, my gut tells me to be afraid.

I don’t know why, probably because I don’t know any of the facts and therefore it’s the fear of the unknown. I’d be lying if I said the risks didn’t make me nervous.

People Over Profit

My limited knowledge of clinical trials tells me that some are government funded; whilst others are funded by the pharmaceutical company that will go on to sell the drug. If I’m going to participate in a clinical trial, I need to know that it’s being led by an organization I trust.

If the UK’s National Health Service (NHS) tells me they’re running clinical trials for fibromyalgia, I will be more likely to participate than if Pfizer got in touch to say they’re doing the same. Ultimately, it’s in Pfizer’s interest for the drug to have a particular outcome and I’m somewhat nervous about regulation within the pharmaceutical industry as a whole.

Friends of Friends

It’s one thing to read something online, but it’s quite another to hear it from someone you know. You trust it more, you remember the details and you have the opportunity to ask questions and talk through your concerns.

I don’t know anybody who has participated in a clinical trial. Maybe that’s why they seem so alien to me. If my friends start telling me what an awesome experience it is, I’ll be sure to reconsider.

Complex Medical Terminology

As part of my research for this article, I read a lot of recruiting adverts for clinical trials. I am going to assume that they’re written for medical professionals who are then supposed to contact their patients, because I barely understood a word.

Part of the reason I write my blog is to try and humanize everything that we’re going through as chronic pain patients. Medical terminology has its place, but when I’m nervous about the effects of a clinical trial, I’d like to see the patient information displayed as simply as possible.

What am I missing? Have you been part of a clinical trial, and would you recommend it?