

## Epistemically Challenged: Julie Rehmeyer

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Epistemically Challenged is an opinion series about how each one of us explores knowledge. In this installment, we spoke to award-winning math and science writer Julie Rehmeyer.

**M**y thinking about science has been very strongly affected by my experience with chronic fatigue syndrome (CFS). Science has not served this illness well at all, and as a result, my perspective on the illness has been pushed from, “Okay, I’m going to use science to get better!” to “Wow—science is pretty shitty here.” I haven’t had the luxury of saying, “Fine, I’m going to go work on something where the science is better.” *I had to get better.*

The experience has made me far less trusting of the institutions of science, and that has affected how I look at science more broadly. The CDC [Centers for Disease Control and Prevention], for example, **has made some pretty big mistakes** in handling CFS, mistakes that continue to hurt patients. For example, they created and pushed and continue to use a **really broad definition** of the disease that includes lots of patients whose **primary problem is depression**, or who may be just tired and stressed. Their definition doesn’t require the symptoms that are especially characteristic of the illness, particularly the way that too much exertion makes patients really, really sick (and for severely ill patients, by the way, “too much exertion” can mean brushing their teeth).

The CDC’s definition meant that ten times as many people qualified as having the disease—2.5 percent of the population! That has really confused the research, leading to findings that make it look like CFS is all in people’s heads. The CDC has also done a terrible job of educating physicians about the disease, recommending exercise and therapy prominently but pretty much nothing else. They even suggest that gradually increasing exercise can get bedbound patients back to daily functioning, though even the most optimistic studies show that to be unrealistic, and worse, exercise can permanently injure CFS patients unless done with extraordinary care.

And the problems go way beyond the CDC. In 2011, *The Lancet* published **a study** claiming that graded exercise therapy and cognitive behavioral therapy are “effective treatments” for chronic fatigue syndrome and often lead to recovery, and the media trumpeted these findings around the world. Pretty much every mainstream scientific institution endorses this work. But when you dig down into the details, you find that **the data doesn’t support the researchers’ claims**. The most amazing problem

(among many) is that “recovery” was defined so loosely that patients could get sicker over the course of the study and still be said to have recovered! But this study is considered top notch, gold standard work. The media has fallen down here too—no article in the mainstream media has ever seriously analyzed this study, even though patients are being injured by it regularly.

The whole thing has been really shocking for me. It’s had a huge impact on my perspective on science and the world as a whole, and there are a lot of controversial issues where my emotional stance has changed in a really big way. It doesn’t affect me so much on an intellectual level, on how I evaluate things; but I often find that my emotional standing is with the people who are perceived as anti-scientific.

Take something like GMOs. I’m pretty convinced that the direct health risks from GMOs are low; however, I get really, really pissed off at those articles that criticize people who oppose GMOs for being unscientific, the ones that say these anti-GMO people should just shut up and get on the band wagon, and that if they oppose GMOs, they’re as unscientific as climate deniers.



Rehmeier's [oped](#) on Chronic Fatigue Syndrome from the New York Times

First of all, it’s a really complicated issue with a very different character from climate science. There’s no credible scientific position that climate change isn’t happening or

isn't caused by human activity. But with GMOs, there are so many different facets to deciding whether they're a good thing and whether it's a good idea to eat them. Scientists, and ordinary people, disagree on which of those factors matters most. My take on the science is that yes, it's unlikely that genetic modification inherently makes food unsafe, but I do think people's health concerns about the increased use of glyphosate on Roundup-ready crops are reasonable. And then there are environmental and social concerns that are very real and very complex.

On an emotional level, though, I think about a patient with CFS deciding about this. If you're that person, what is your experience with the world? Your experience is that the scientific establishment has treated you badly. You're sick and you don't know why and you don't know what to do about it. Having seen what the CDC has done with CFS, you don't trust their advice or research. You've seen **friends injured** following the advice of respected doctors to do graded exercise therapy, and you've learned to keep yourself safe by relying extensively on the **experiences of your fellow patients** rather than purported experts. You seem to be more vulnerable than most people to all kinds of things—so something could be safe for 99.9 percent of people and not safe for you.

Is it unreasonable or irrational or unscientific for you to say you don't want to eat GMOs? I don't think so.

The place this gets a lot more tricky is with vaccines. All those arguments that I just made apply to vaccines. If you've got CFS and you've got two kids who are also getting sick, do you want to vaccinate them? You know you and your kids have got some kind of neuroimmune problem, and you've heard a lot about vaccines causing neuroimmune problems. Not only do you not trust the CDC, more generally, you've learned to mistrust science with an agenda. The forcefulness of the pro-vaccine side increases your suspicion, leaving little room for a rational discussion of the risks—risks that may apply disproportionately to your children. Giving your kids vaccines is actually a really frightening decision. It's a hard thing to do.

But at the same time, who the hell do you believe? Maybe your kids are more likely to be hurt if they *do* get some nasty bug. Maybe they're not more vulnerable to problems from vaccines—after all, it's really hard to figure out who *is* vulnerable.

And of course, this is a circumstance where the ramifications of your decision go far

beyond you and your children. Making a good decision about vaccines really matters, for all of us.

That's all a preamble to the problem of knowledge that's on my mind: How do we evaluate as individuals the significance of science? How do we do it in the context of incomplete knowledge and insufficient time—and with the Internet providing every opinion you might want to find?

We do it by relying on people that we trust, more or less. But how do you figure out who to trust? I'm curious about this partly on the individual level, thinking about how to make these decisions better, and also on the societal level, wanting to understand this process better in order to influence it more effectively.

I feel like scientifically minded people very often take the attitude of, "Well, you should do what the science says. That's the answer. You should do what science says, because you know, scientists are smarter than you. They've looked into it more than you have, they've thought about it carefully." When you're a scientifically minded person who has been more or less in the mainstream of life—you haven't been forced into a scientific swamp like CFS—that argument can feel compelling. But there are a lot of people who don't fall into that category, and it's clear that they don't find that argument compelling at all. And really, they don't have that luxury.

The perspective that I'm coming from with my experience of chronic fatigue syndrome is a fairly extreme one because CFS patients have been so mistreated and science has functioned so poorly for them. But there are a lot of people who have reasons—good reasons—for being suspicious of mainstream scientific opinions. And really, we should all have a degree of suspicion. Think of the results of John Ioannadis, who has found that nearly half of the highest-quality medical studies are likely to be **wrong**. It's shocking and scary. Or think of nutrition research, and how the federal agencies strongly pushed a low-fat, high-carbohydrate diet for decades, even after research made it clear that that was lousy advice. Science is hugely valuable, but it's also hugely difficult, and skepticism and humility are essential to its good functioning.

And frankly, even if people are skeptical of scientific findings to a degree that seems inappropriate, that attitude is probably not coming from stupidity or pig-headedness. It's often coming from a different set of experiences, a different set of needs—



participation in a culture with different attitudes. Those of us who value science need to understand their perspective better, and that understanding needs to grow out of a place of huge compassion. You've got to enter their world and figure out their decision-making processes, rather than saying "Okay, you people come over to my world, where it's all really simple and clear."

— Julie Rehmeyer, a freelance math and science writer, is the recipient of the 2015 [Excellence in Statistical Reporting Award](#) from the American Statistical Association. You can read more about her [here](#).

## 28 Comments



**Honeybee** on September 9, 2015 at 1:50 am

Thank you Julie Rehmeyer for an article that brings out some very excellent points with regards to how science has not served the ME community well. Let's hope that those that need to hear start listening.

Reply



**Jaime** on September 9, 2015 at 2:01 am

This is brilliant. Thank you for articulating what so many of us have gone through, especially those of us with backgrounds in science. You can get caught up trying to be an expert in every field of medicine, since there are few others on whom you can rely; but of course this isn't realistic or reasonable. Instead, you create a network of ill researchers whose understanding of science you trust, and you become a scientific community, if your thinking hasn't degraded too badly by the time you find them.

If you had asked me before I got really sick who it was who would post long, involved conversations about medicine online, I would never have anticipated the quality, intellectualism, and professionalism represented by the ME/CFS community. Everything they state is cited, everyone is trying new things and reporting back, there are few post hoc arguments, remarkably little jumping to conclusions... which is more than I can say for

Reply