‘I want to help humans genetically modify themselves’

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Josiah Zayner with his Crispr gene-editing kit. Photograph: Courtesy Josiah Zayner / The ODIN

Josiah Zayner, 36, recently made headlines by becoming the first person to use the revolutionary gene-editing tool Crispr to try to change their own genes. Part way through a talk on genetic engineering, Zayner pulled out a syringe apparently containing DNA and other chemicals designed to trigger a genetic change in his cells associated with dramatically increased muscle mass. He injected the DIY gene therapy into his left arm, live-streaming the procedure on the internet.

The former Nasa biochemist, based in California, has become a leading figure in the growing “biohacker” movement, which involves loose collectives of scientists, engineers, artists, designers, and activists experimenting with biotechnology outside of conventional institutions and laboratories.

Despite warnings from the US Food and Drug Administration (FDA) that selling gene therapy products without regulatory approval is illegal, Zayner

sells kits that allow anyone to get started with basic genetic engineering techniques, and has published a free guide for others who want to take it further and experiment on themselves.

Was administering a dose of Crispr on yourself an experiment, or a stunt to show what amateur scientists/biohackers can do?
Both. The technical feasibility of what I did is not under question – researchers have done this many times, in all sorts of animals. But there's a barrier – people are afraid of it, and just talk about the possibilities in humans. I wanted to break that down, to say "Hey look, the tools are inexpensive, and somebody with a bit of knowledge can actually go through with these experiments".

I chose to start with the gene for myostatin [a protein that regulates muscle growth], because it has been extensively studied, and it produces an obvious change if it has worked.

Watch a video of Josiah Zayner injecting himself with a DIY gene therapy.

So, how is your arm looking?
In similar experiments with animals, you only start to see results after four to six months of treatment. I would expect that the DNA in some of the cells of my arm has changed, but I am still working on developing assays [tests] to try and detect that. As to whether the actual size of the muscle changes, I'm more sceptical.

Changing the way one gene behaves can have a huge number of knock-on effects on the way other genes are regulated or expressed. Do you really know what you're doing?
It's a good question. These things are complicated, and obviously with things like this there are lots of unknowns. I look at what the possible negative outcomes are and ask: "Are those risks insignificant enough that I'm willing to undertake this experiment?" Based on the data I read, for a local injection the answer was yes. A treatment that blocks myostatin throughout the whole body? That would be much more hazardous – you would be messing with the muscles of your heart.

You support the idea of people attempting gene therapy and other experimental procedures on themselves. What's wrong with the existing system, where treatments are thoroughly tested by professionals before being approved for use?
If we're going to do these experiments you have to balance two things: how many people can possibly die from testing their own products or making them available prematurely, versus how many people have genetic disorders and are just dying because they don't have access to them. I think there's a huge imbalance, where we're overprotective of hurting people instead of offering a chance to millions of people who are dying right now.

As human beings we're very big on freedoms, equality, equal rights. What's more of an equal right than being able to control what genes we have? I think people should be able to choose that. I'm not saying anything I can do can

help treat people, but treating things genetically is the ultimate medicine.

▶ Q&A

What is Crispr?

I grew up in the 90s with the computer hacker movement, the development of the internet – the whole open-source movement was amazing. Who created Linux, the most used operating system ever? Not students from Harvard or Cambridge, but Linus Torvalds, a student in Finland working in his apartment.

I don't think for a second I'm going to be the mastermind behind a great biotech revolution, but I think there's some brilliant person waiting to be discovered out there that could be.

In another recent biohacking experiment, a man injected himself with an unproven gene-therapy treatment for HIV which had been developed by biohacking startup Ascendence Biomedical. What do you know about what they are doing, and do you support their approach?

I think they're at a lot more risk because they are trying to work in the medical field, saying they can cure people. I think that starts to get a little more ethically and morally sketchy, and the government will certainly crack down on that.

The reason we have hospitals is that it's not just one random person giving you their opinion; there is oversight, checks and balances. When people start proposing new treatments without data to back them up or without consulting people, I think "Hey, be smart". Get a second opinion, third opinion, ask doctors, ask other biohackers. Trying a therapy that doesn't work instead of your medication obviously could be worse.

The problem is, it's like the freedom of speech thing: it sucks sometimes. If I say I want the freedom to test something on myself, it means everybody does

– even people who are stupid or want to do crazy stuff.

But if you say people should experiment on themselves outside of the traditional clinical trial system, surely that's exactly what will happen? There will be a grey area where people are halfway there, or guessing what the effects will be.
Yeah. I don't know – honestly, I would never put me in charge of running this stuff for the FDA or the government. I think there are people who know how to make the rules to protect the most amount of people.

People are going to get hurt with this stuff and I feel ethically terrible about that, and I don't know how to prevent it. I see these instances of people doing crazy stuff and I'm like, "No, that's not what I meant! Why are you injecting things in your eyeballs?".

I have this very libertarian side of me that says people have the right to do whatever they want with their bodies. But I also have this part of me that says "Be knowledgeable! Base it on scientific data!"

What do your family think of what you do?
I usually hide stuff I'm about to do from them, in case they try and talk me out of it. If I decide to do something, it's because I've carefully weighed up the pros and cons. They won't understand how much research I've done. My mom supports me, but thinks I'm crazy. She was so sad when I left Nasa.

Last year, you performed a DIY faecal transplant on yourself. How did that go?
Yes, I did a DIY faecal transplant to help with my gut health issues. It still blows my mind the effect it had, and DNA samples showed I did manage to change the makeup of my gut bacteria. I don't exactly recommend the course of action I took, because there are safer alternatives to DIY. But if people have no access to those I support their choice to try it. Faeces is quite strictly regulated in the US, like a drug, so people travel to the UK where there are clinics.

Where do you and other biohackers get the equipment, tools and chemicals to conduct genetic engineering at home?

People don't know that generally the same resources that are available to scientists are available to non-scientists. I can just order DNA online and they ship it to my house. If I want to get some sequencing done I send it off to a company and they'll do it for me. It's really inexpensive – we're talking $6 to get a sample sequenced, or $10 to get a piece of DNA.

What are you working on next?

We have always been slaves to the genomes we have, and giving people the ability to change that almost changes what it means to be human. It seems so sci-fi and made up, but we've been genetically modifying humans with gene therapy since the 1990s – it's just been very few people and for medical reasons. I want to help humans genetically modify themselves.

If DIY genetic engineering becomes commonplace, as you hope, what do you think the world will be like in the future?

To me it's like *Blade Runner*, where he goes into that back-alley science lab and there's the guy making eyes. I imagine people going to some place like a tattoo parlour, and instead of getting a tattoo they pick out some DNA that makes them muscly, or changes the colour of their hair or eyes.

DNA defines what a species is, and I imagine it wouldn't be too long into the future when the human species almost becomes a new species because of these modifications.

When scientists first started altering DNA just to make, say, tomatoes ripen differently, there was immense public concern. Do you expect the general public is going to be supportive of people modifying any organism, including people, in any way they can, in their garage?

The whole thing with GMOs [genetically modified organisms] was that it was "us and them". They have the power to modify plants and we don't know what they're doing, and have no control over it, and so we are against it. This

technology that I'm trying to do is for all of us. Whether you're a big corporation or somebody in their basement, you have access to this stuff – everybody does. People respond very positively to that. We'll see what happens. I'm sure we'll get a different response when people are doing it every day, or when the first person decides to try and give themselves a tail or something.