

“We are all Billionaires in Terms of our Genome Data”

Interview at the Festival of Genomics & Biodata, 29th-30th of January 2020 at the Business Design Centre in London

With Professor Ernst Hafen (ETH Zurich, Institute of Molecular Systems Biology)

Interviewer: Drenusha Sejdiu, Frontlinegenomics.com

FLG: Could you give us an introduction of yourself and the work you do?

I'm Ernst Hafen and I'm a professor at ETH Zurich. I'm a biologist and very much interested in genomic data and even more interested in the fact that we as individuals can contribute to medical research by providing access to our data.

FLG: What motivated you to do what you do?

I'm a model organism biologist and I worked with fruit flies for 30 years. They are very simple organisms and can tell you a lot about the basic principles of biology. But if you want to understand how you and I are different, then you must go to humans. Humans can talk about their phenotypes and visit a doctor when they have something. Flies can't. So that motivated me to concentrate more on the engagement of citizens in science, especially in health research.

FLG: How can people have control over their own health data and are there any ways this is currently being controlled?

I usually make the analogy with money and your salary. We all have a bank account, and your salary comes into your bank account and you have absolute control of what to do with it. In the future, we won't only have a bank account, but we will also have a data account. Data has an advantage over money in that it can be copied. Doctors can keep a record of your medical history and it's easy to get a copy of that. You can also get a copy of your genome data and what your phone records 24/7. If all these copies go to your account and you want to share it for a second opinion or to participate in a research project, you can decide, and it gives each of us a very powerful position in this healthcare system.

FLG: Why are we seeing an increase in the amount of genomic data available?

It's a technological advancement and it's easier to get this data now. We still need millions of data sets in order to make sense of that, and one data set is not enough because we're all different. We all differ in our genomes by 1 in 1000 base pairs. It's very little, but it makes all the difference that we see. Understanding how these small differences translate into the difference in susceptibility to disease is a challenge that we need everyone to participate in.

FLG: Why is it important to make biodata sustainable?

Biodata is not just a one-time thing. In contrast, genome data is as you sequence it once and then you have it. All other types of data, such as your blood glucose levels, fitness levels, BMI, etc, all change over time. In order to make sense of what keeps you healthy, we must look at the whole trajectory, ideally from cradle to grave.

FLG: Are there any challenges that need to be overcome?

One challenge is to convince people that it's the individual who should be in charge of their data because they are the maximal aggregators of their data. This may be abstract, but coming back to the topic of money, the economy works because you and I spend our money differently. It's not the state who says you can buy this pair of shoes or this car etc. It's you who decides. We are the maximal aggregators of our data, even though Google probably knows more about our health than your physician does. You could know even more about our data since we can aggregate google data with NHS data and genome data. Only you can do that.

FLG: Do you see any major breakthroughs happening in genomics over the next few years?

I see breakthroughs coming from the help in interpreting genomics because it will be combined with phenotypic data sets not only medical records, but also with more data from healthy people. We continuously record health relevant data, and bringing this together will tell us not only why we're sick, but what keeps us healthy. That's what we all want.

FLG: Why have you decided to participate at the Festival of Genomics this year?

I was happy to fill in for a colleague who couldn't attend, and I certainly didn't regret it.

FLG: Anything you want to add?

Personal data and health data in particular are unique assets that we are discovering as individuals, and its one of the assets that is equally distributed amongst people. No matter where you're from, we are all billionaires in terms of our genome data. It's one of the few assets that are equally distributed, and we should make sense of that.