

A BRIEFING ON TRENDS, IDEAS, VISIONS AND POSSIBLE FUTURES

# SCENARIO

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Copenhagen Institute for **Futures** Studies

LONE FRANK AND THE ART OF EXPOSING EVERYTHING

## OPEN SOURCE GENOMICS

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Lone Frank, the science journalist, has just written a personal, bittersweet and extremely informative book about her voyage through the genetic tests of this world. She has a PhD in neurobiology and is an advocate of making genetic information available to everyone. And she is not always “nice”. On the other hand, she is honest. Blisteringly honest. Read how SCENARIO stepped directly into the universe of Lone Frank from the very first second.

# NOT ALWAYS NICE

*By Morten Grønberg*

**D**amn! This place is ugly.” Lone Frank has just arrived and is passing my office on her way to the conference room where I will shortly be asking her questions about the book *My beautiful genome*, which she has recently published.

I agree with her and mumble something about the fact that we HAVE actually started to redecorate the premises, while making a mental note that she has just opened our meeting with an insult. Strange, considering that she is meant to be on a charm offensive to talk about her new book.

However, I knew in advance about Lone Frank’s honesty and scathing comments. The book we are to talk about actually has the author’s own unfriendliness as a sub-theme, in that on her journey she receives plenty of evidence that this particular character trait is a pretty dominant part of her personality.

This is made clear, for example, with the aid of a psychological personality test. Savour this passage from the book where a test provider is giving Lone Frank feedback about the results of her test:

“It looks like I scored pretty low on the friendliness dimension, or what?” “Yes,” replies Skovdahl Hansen slowly. “Yes, you do. In fact, it isn’t possible to score any lower.” The statement hangs in the air between us for a moment, and then Skovdahl Hansen admits that he has not been looking forward to meeting me since he analysed the data.

“So that’s about as low as you can get,” says Lone Frank with a chuckle when, later on in our interview, we start to talk about this example and the generally brutally honest self-presentation of which the book contains a great many more examples.

I guess I should have been prepared to hear a fair amount of what can best be described as “straight talk” during the interview. But I had never imagined that it would start from the very first exchange of words.

However, it becomes apparent in the conference room that Lone Frank is not really a monster at all. In, fact, I like her. Or perhaps more precisely, I still like her, because even though I have only met her briefly before our interview today, I have been following her work through reports in the daily newspapers for the past decade. In my opinion, she is the best scientific journalist in Denmark, specialising in material centred on the natural sciences. She is a journalist whose articles I *always* read. I am quite simply fascinated by the contents of her new book.

## THE BOOK

*My beautiful genome* is the story of a future that appears to be well on its way. One where everyday people will be faced with making crucial personal decisions based on results of the genetic tests that are set to become cheaper and cheaper, and thus more and more widespread and common to take. Lone Frank seeks out the places where genetic research is being carried out, where the industry is based, and she then interviews the appropriate researchers – including true heavyweights such as James Watson, who was one of the recipients of the Nobel Prize in 1962 for his work on identifying the structure of DNA.

She describes both opportunities and threats for the future (with emphasis on the former, however) and touches on subjects such as consumer genetics, neo-eugenics and open source genomics. First and foremost, however, she makes use of her own person and allows herself to be the subject of a variety of more-or-less serious tests. The entire exercise is centred on discovering whether she should expect to die of breast cancer, as other members of her family have done. She is also seeking the answer to the almost primordial question: Who am I? This is the driving force behind the narrative.

Lone Frank herself formulates the issue from the starting point of the day when she lost her surviving parent:

*“First and foremost she makes use of her own person and allows herself to be the subject of a variety of more-or-less serious tests. The entire exercise is centred on discovering whether she should expect to die of breast cancer, as other members of her family have done.”*

“At 43, I have reached the age where the opportunity to have children should probably be considered only theoretical. That is pretty much OK, because I have never really wanted to have any, but to have no parents and no children is to be truly unfettered and free-floating. When you cannot see yourself reflected in anyone else, then it is like you occasionally lose sight of yourself.

“Where do I come from? Who am I? Will I end up like my parents? What will I die of? And when? These are questions that we have always asked, but they can now be asked very specifically and attached to something delightfully tangible: DNA. Our hereditary material and the thousands of genes it contains.”

It is this link between the intensely personal and the more objective, natural science research that justifies the “novel-like” aspects of the book that a number of reviewers have noted. This is because it is personal for the right reason, i.e. not attempting to be private but rather to seek out something both universal and human.

This is an intention that Lone Frank makes clear from the very start through her introductory quotation from the Danish artist Asger Jorn (“The only way to be universal is to be deeply personal”) – and she succeeds in her aim.

Because even though the book provides us with insight into a family history that includes psychological problems, depression, alcoholism and even suicide attempts, and even though I now know that Lone Frank herself would rather have larger breasts, the descriptions are always associated with the attempt to understand where everything comes from. This book is “genetics meets the personal narrative” – a gripping combination.

While it is true that hereditary material consists of thousands of genes in a combination that is unique to each and every person – an extremely individual perspective – mapping this material simultaneously deconstructs the individual into such abstract subsidiary

components that it almost completely dissolves the human perspective. It is clear that we are dealing with the huge in the miniscule. And vice versa.

## THE CONFERENCE ROOM

Back to the conference room and to Lone Frank. I start off by asking her if the brutally honest style of the book is intended to mimic something, such as the idea of open source genomics, which concerns the publication and sharing of one’s test results with everyone else on the Internet.

Lone Frank: “Yes. I am a keen advocate of genetic information being available to everyone, so I must naturally lead by example.”

*SCENARIO: Can you then tell our readers what you are going to die of one day? I couldn’t find it anywhere in the book...*

Lone Frank: “It will probably be something cardiovascular. This is the area of my profile that is most vulnerable. The rest wasn’t as bad as I had feared, particularly with regard to breast cancer – which was something I was really worried about. But I cannot say with any certainty, because it turns out I have excellent genes and there is nothing that really stands out.”

*SCENARIO: You have been writing about the field of gene technology for many years, but what is new in this book is that you take a load of tests. What surprised you the most?*

Lone Frank: “What was most surprising was actually my own reaction when I was to see the results of my genome scan, which is one of the different tests that reveals something about my risk of illness. To start with, I did not want to look at the results at all, but after I did, my reaction was not really that strong. I did not feel worried about the future or insecure, as the sceptics have otherwise predicted that people will feel in that kind of situation. Rather, I felt that this was good information to have. I feel more at home in myself now, more at home in my biology.”

*SCENARIO: But of course your test results were fine. Doesn’t that make it easy enough to be happy and unconcerned?*

“I have an elevated risk of glaucoma, which could make me go blind. This is a result that, excuse the pun, I could stare at until my eyes go fuzzy. But my reaction is: then I’d better get my eyes checked! My point is that it is wrong for the sceptics to assume that people cannot handle finding out information about themselves. Most people can easily deal with it. It is only those of a particularly nervous

disposition who would perhaps be better off not knowing what I now know.”

*SCENARIO: On the subject of doing something yourself, can people use a gene profile – like the one you had done – for purposes of active risk management?*

Lone Frank: “There are some things that you can certainly influence. I have some really terrible genes in relation to depression, stress and the like. But thanks to the tests I find it easier to understand why I have a tendency to depression and why I am exceedingly bad at dealing with stress. It means I can say to myself that if I want to live an easier life, then I need to avoid exposing myself to stress. Of course, I could also try saying to myself that I can perhaps attempt to work my way out of this situation now that I understand that it is a biological tendency I have. Even though our hereditary material is locked in, our brain is extremely versatile. And the more you know about it, the more you can influence it.”

*SCENARIO: What does the future look like in this field?*

“Genetic tests are relatively cheap, but it is still expensive to have your whole genome mapped out. In a few years, however, the mapping process will become generally affordable. Within a generation, it is likely that people will be able to have their genome mapped out at birth. The coming generations will grow up with a large amount of genetic knowledge about themselves, and with genetic insight – i.e. the capacity to make use of the results. Moreover, it will become possible to use the results in more and more areas. It will be rather like the situation of the present generations, who are born with the ability to master computer technology.”

*SCENARIO: You write in your book that your partner is actually a poor genetic match for you – in any case if you were to have children together, which you have chosen not to for other reasons. A similar test revealed that your colleague was a much better match. It could be said that this kind of information has the potential to eliminate the magic from the world for the coming generations. For example, if they know in advance who is the best genetic match for them, then they may stop having children with the people they fall in love with...*

Lone Frank (moving forward on her seat and raising her voice): “Oh shit, there are simply so f\*\*\*ing many people who say that. And all I can do is repeat again and again that precisely the opposite will happen! The more you work with nature and biology, and the more you study it in depth, the more magical the world becomes.”

## MY BEAUTIFUL GENOME

The book *My beautiful genome* is subtitled *Self Discovery in the genetic age*. It was published in Denmark by Gyldendal in September 2010. It will be released in an English version in the spring/summer of 2011 by Oneworld Publishing. A Dutch version is planned for May 2011 by Maven Publishing and a German version by Hanser Verlag for the fall. See excerpt from the book on pages 65–7.

## OPEN SOURCE GENOMICS

Open source genomics combines the basic web-related open source idea with the phenomenon known as personal genomics – the mapping of the genes and genome of each individual. It is getting cheaper and cheaper to have this done, and this means it is becoming increasingly popular. Open source genomics involves sharing one’s genetic data with others via the Internet (Lone Frank calls it Facebook genetics). Not only does this provide opportunities for anyone with a good idea to conduct research using the material available, but also that contributors have the chance to follow what is going on, to compare themselves with others and (for example) find relatives and potential partners on the basis of genetic matches. While personal genomics is mainly about each individual’s understanding of his or her own genetic background, and the development of medical measures tailored to specific genetic set-ups, open source genomics is primarily a shared endeavour.

*SCENARIO: But this is hard to understand, when the purpose of genetic research is to create more transparency. The lack of transparency – or rather, the absence of visibility of some specific things – does something to us ... For example, in years gone by, writers described eroticism indirectly and with great finesse, because it was “not done” to write about such things directly. This resulted in the development of a finely nuanced art of insinuation, whereas novels today are more obvious and direct. Isn't there a risk that the same kind of thing will happen to our lives?*

Lone Frank: “I don't think your analogy holds water. Our opportunities for fesses are growing and growing. It is when you start to know something about how the world is put together, how people are built up, that everything becomes more and more incredible. It surpasses any fiction or mythical perception of the world. And it is fascinating to know about the mechanisms of why we match our partners, and why we are attracted to some people and not others. After all, there are hard facts to back it up.”

*SCENARIO: Another interesting phenomenon you mention is the book is that of “genetic McCarthyism” – i.e. the practice of attacking political opponents using the DNA information that we all scatter around. Can you explain that a little more?*

Lone Frank: “The concept is linked to the anxiety that exists in the United States that genetic information about politicians might be used for smear campaigns. Specifically, there were rumours during the 2008 presidential campaign that Barack Obama's staff collected everything he left behind so that no one could snatch the DNA of the presidential candidate.”

*SCENARIO: But McCarthyism was a witch-hunt aimed at people with different political convictions ...*

Lone Frank: “Yes it was, but the fear today is that if a politician has something ‘unpleasant’ in his or her DNA, this could be used as a weapon by his or her opponents. We are talking about a technological revolution here, and just as with all revolutions, some people will use the progress made for negative purposes. And I have no doubt that we will witness some terrible things during this change-over period. For example, someone may find something in the genome of an otherwise promising presidential candidate and think ‘that's not the kind of person we want for president! Do we really want a president

with an elevated risk of Alzheimer's?’ From a technical perspective, it is possible to map a genome completely on the basis of a lip print from a cup that the candidate used. It is actually quite simple.”

*SCENARIO: Another area that often leads to ethical discussions is the issue of modern eugenics, or what was known as “racial hygiene” in the 1920s and 1930s. You describe in the book how this is already being practised today. For example, doctors have helped an English couple to design a baby to be free of a mutated gene that would otherwise have led to an increased risk of breast cancer. What does the future hold in this field?*

Lone Frank: “Of course, at some point in the future we will start to think about how the next generation is to be put together. What is new is that thoughts in this area will become more individual. The old practice of eugenics was something that the state imposed on people. The state said ‘we need to eliminate the mentally deficient, so we will be sterilising them.’ But this was enforcement – and built on an incorrect genetic basis. Today, we are quick to remove any embryos in which scans reveal abnormalities or malformations. This is also a form of eugenics, but we don't talk about it that much. Nevertheless, we have already started down this path, and it will become more and more widespread. And we might as well call it by its real name, because that will bring the subject out into the open.”

*SCENARIO: In your book, you also describe what you call the “omission system”, i.e. the fact that social pressure will be applied to people who do not have their children checked in time ...*

Lone Frank: “Yes. That is an interesting discussion. The classic reaction to eugenics is ‘That's terrible, everyone has the right to be here, even disabled people’. But you can turn that argument around and ask ‘is it reasonable to demand that some parents, for purely ideological reasons, bring a very sick child into this world? A child who may never know anything other than pain and misery?’ Isn't it just as justifiable to say ‘It is ethically disgusting to do something like that now that we have the technology to avoid it?’”

*SCENARIO: Could this become the dilemma of the future?*

Lone Frank: “One of them, certainly. There are many future dilemmas. Personally, I support the freedom of the individual to a great extent. I also believe in people taking responsibility for their own actions. But not everyone sees things that way.” ■

LONE FRANK

Lone Frank is an author and science journalist with a PhD in neurobiology and a background in research. She works at the Danish newspaper *Weekendavisen* and also takes on the role of debater and a moulder of public opinion in the fields of health, medicine, technology and ethics. She has also appeared on radio and TV programmes and has written four books. Her most recent book, *My beautiful genome*, has just been published.

