

My Beautiful Genome

Prologue

I'm dead tired. For the last hour and a half, I've been run through a whole battery of tests, all designed to shed some light on my personality, my disposition, and my intellectual abilities. I've volunteered to take part in a major research project to examine the connection between specific genes and personality – in particular, a tendency toward depression. We have finally reached the last questionnaire. A young, female researcher is sitting across from me on the other side of a round table, gazing at me cheerily.

"I'd like to ask you some questions about your immediate family – having to do with drug and alcohol abuse, criminality, and psychological illness."

The blonde ponytail swaying back and forth makes her look perky and efficient.

"They're not about you but about first-degree relatives: parents, siblings and children."

"I don't have any children."

"Parents and siblings, then."

"My parents are dead, but I have a brother."

"Whether they're alive or not doesn't matter, the questions are the same," she says. "Let's start with alcohol. Have any of your first-degree relatives had any problem with alcohol?"

"Problem? Problem, you say? Yeah, well, I suppose I'd have to say yes to that. Such as it is."

"Yes...?"

"My father. Some would say he had a certain problem with alcohol."

Starting your day with vodka in your coffee and working your way through with malt liquor might be called by some people a bit of a problem.

"For an extended period?"

"As long as I can remember, really. But he didn't think it was a problem himself as such; he could certainly function."

She flips the first page and follows the instructions.

"Did this alcohol abuse ever lead to divorce or separation?"

"Yes."

She looks at me inquisitively, inviting additional information.

"Okay, three times. Divorce."

The eyebrows shoot up her forehead.

"Well, then. Was he ever sent home from work or incapacitated?"

“No, no.” Of course, not. My father was a very capable and conscientious teacher all his life. He did his job no matter what.

“No problem there,” I say, thinking the worst is over, but then she wants to hear “were there any arrests or DUI convictions?”

“Yes, there were. A few. That is, I don’t quite remember.” I feel like I need to explain this. Provide a defense. All this suddenly sounds worse than I remember it.

“Nothing ever happened. No accidents, I mean. My father was an excellent driver, even when he’d had a few. He was just unlucky enough to get caught. A couple of times.”

“Okay. Good. So, we’re done with alcohol.” She resumes the interrogation with a more optimistic tone.

“Have any of your first-degree relatives had any mental health problems?”

“Yes,” I reply and, of course, I’m immediately asked to provide more details.

“All of them.”

“All of them? Okay. Okay. Where do we start?” she mumbles to herself, leafing through her papers, confused. I want to be helpful and quickly make a list. When I was little, my mother suffered from depression – deep, clinical depression, which was particularly bad in her last few years. My little brother has had a few bouts of his own, and my father was manic-depressive, diagnosed at the age of 60 when it had come to be called bipolar disorder.

“So, he had manic phases?”

“I’d have to say yes.” I have a sort of flashback to that one Christmas when he pretty much did not sleep for a week but trudged around the house clutching a stone-age axe in one hand and an old Bible in the other. Talking and talking and talking, becoming more and more incoherent. Finally, we had to hospitalize him.

“Any psychoses?”

Here, I dig my heels in. After all, we’re not family of lunatics.

“No. Nothing like that,” I reply. “Except, maybe ... there were some episodes where my father believed someone was prowling around the garden shed at night to steal his tools. There was also a period when he thought someone was talking to him through the heating pipes, but that was only for a short time. It went away with a little Zyprexa.”

She looks down at her notebook again and adds a note. I can see it says “mild paranoia.”

“Has anyone other than your father had psychiatric treatment?”

“We all have.”

“Medication or consultations with a psychiatrist?”

“Both,” I say and, then, something comes to me. “What about suicide attempts, do they count?”

The young researcher nods silently and finds the box on the form for suicide attempts.

“Okay, there were two of them – two I know about, anyway. My father. My mother on the other hand only talked about it.

The blonde doctor stares resolutely at her papers, as she asks the final questions, having to do with narcotics abuse. Here, I can answer with a clear conscience that we in my family have never had any problems with drugs. Of course, not.

“You’ve never yourself taken narcotics of any kind?”

“I drank some home made hemp schnapps on New Year’s Eve at the beginning of the ’90s, but that’s all. And it didn’t work.” Or, rather, it worked so well that I slept through the whole party, which reportedly took place in the great hall of Copenhagen’s squatter town Christiania.

“About alcohol,” she says, “I also have to ask you about yourself. How many drinks do you have during the course of a week?”

“It must be around 14,” I lie promptly and deftly. For some reason, 20+ doesn’t sound good, and the intention is always to stick to 14. “You know – two glasses of red wine a day, purely for medicinal purposes. It’s because red wine contains resveratrol, which is healthy for pretty much anything. Heart, blood pressure, cognitive faculties.” She nods enthusiastically.

“Fourteen drinks, that’s within the National Board of Health recommendations. Good, good,” she says at last, smiling an almost liberated smile.

“Yes, well, I don’t think I have any more questions.”

But I do. I have questions. They’ve been smoldering quietly in my mind and were probably the real reason I volunteered when I heard about these genetic studies.

If I am to be brutally honest, there is a direct connection between my interrogation here at the round conference table and the small provincial hospital room, where I held my father’s hand, when he died on a summer day over a year ago. It may sound macabre or bizarre, but that’s how it is. Because, when it comes down to it, what is an interest in genetic information all about? It’s about heritage, history and identity.

There I sat in a stifling hospital room with the person I loved more than anyone else in the world, unable to do anything except wait for the end. And when it finally happens, when my father – my father – is simply gone from one moment to the next, a single sentence begins to swirl somewhere in the back of my head: *I’m an orphan.*

I’M AN ORPHAN!

It was an icy sensation not just of being alone but of being without a source, without a history. Now, there was no one who had been witness to my life all the way back to a time before I could remember it myself. No one who could see and describe the common thread that ran between how I was as a tot and what I later became, what I am today. The past, in its way, was gone. And the future – well, you could see an end to it. At 43, I’ve reached the age when the chance of having children is pretty much theoretical. That is fine with me, because I’d never seriously contemplated having any, but being without a source and without offspring is to be floating somewhere up in the air. When you can’t see yourself in any other human being, it’s as though you lose sight of yourself.

Where do I come from? Who am I? Am I going to be like my parents? How will I die? And when?

These are questions humans have always asked, but now they can be asked very pointedly and put to something wonderfully tangible – DNA. And, by necessity, I must ask these questions of biology. I'm not only a biologist by training; I'm deeply fascinated by the human being as an organism. As the miraculous result of myriad microscopic processes unfolding.

It reminds me of something my father said to me countless times over the years, when he was in a sentimental mood or I needed cheering up for one reason or another.

“My dear daughter.” There was always a special emphasis on dear. “You possess an incredibly fortunate combination of genes. You got all the good stuff from your mother and me, but you avoided all the bad stuff.” Here, there was a little pause. “Well, apart from the depressions. But, otherwise, you've got nothing but trophies on the shelves.”

What, as a child, do you say to that sort of thing? You roll your eyes and shrug it off. Parental pride is, of course, good for your fragile ego and limping self-esteem, but you also know that it's way off the mark.

“Stop it, Dad, you're talking nonsense.”

When I was young, I definitely did not see myself as the slender, green top shoot of a majestic tree with stout branches and meandering roots. I was my own person with my own will, quite independent of previous generations and their idiosyncrasies. What could something as abstract as their biological legacy mean to me, an individual who was not only perfectly capable of thinking for herself but had no thought but of moving forward? Absolutely nothing.

Now, it's different. Now, it suddenly means something. There is a nagging, insistent need for a connection to the past. Now, I would like to know something about my heritage. To know exactly what variants and mutations have been left in my genetic lunch pail and what they mean for who I am. I want to understand how my accidental biology has shaped my life. What opportunities and limitations it has given me.

Of course, in front of the mirror, I can see my heritage chiseled directly and not always entirely happily in my physical features. The pronounced nose is clearly from my mother's family, where you can see it all the way back in the sepia-toned portraits of my great-grandfather. My thin, bony frame, on the other hand, comes from his wife – my grandfather's crazy mother whom everyone was afraid of. A stingy shrew of a woman with a gift for domestic tyranny whom I vaguely remember from childhood visits to an apartment permeated by the smell of mothballs and bursting with mahogany furniture and crocheted doilies. Then, there is my somewhat too elongated, slightly plump face and my mouth with its narrow lips, which are clearly a package deal from my father via my paternal grandmother's side of the family.

It is also undoubtedly from there that I get my chronic tendency toward sarcasm. Sometimes, I can clearly hear my father's voice in the zingers spurting from my own mouth, and I can almost feel his facial expressions in my own features. But is this sort of inheritance carried in your chromosomes or created by nurture alone? Is it just rigorous training since childhood or is there some biology in there? How does all this

stuff work that you cannot see on the outside but constitutes what is really interesting about a human being?

“It’s not because I like saying this, Lone,” said a well-meaning friend from university many years ago, “but your personality is against you.” That was around the same time an American girlfriend called me “brutally honest”. A judgment that made me feel all warm inside and happy about my self until she put her hands on her hips and shouted: “It’s cruel! Don’t you understand that people despise honesty?”

But how much of my apparently unattractive personality and my psyche can I blame on tiny variations written into my DNA? Is it the combination of a few unfortunate genes from two different families that give me recurring depressions and a consistently dark out look on life, or do they both derive from an upbringing that was, at times, challenging – to say the least?

There is also the question of physical ailments. Not that I’m plagued by illness or anything – apart from a touch of rheumatism in the innermost joint of my right big toe, which makes shoe shopping difficult and high heels impossible. But what is in there, and what is waiting for me out in the future? Will I die like my parents? Will I be hit by breast cancer at a young age or have to take pills for my heart and blood pressure for years to come? How well can a genome predict this sort of thing? And if you know the prognosis well in advance, can the future be rewritten?

We can finally begin asking all these questions, because something revolutionary has happened. Genetics is no longer just a matter for scientists and experts but is about to be something quite ordinary and everyday. Something anyone can grapple with, because genetics is about to become a serious, practical possibility for everyone. There is an interesting parallel to the world of computers. Originally, computers were large, complicated machines – mainframes – that were found exclusively at universities and institutes duly screened from the layperson and only available to the initiated specialist. But then the technological dikes burst, prices fell dramatically, and computers became a tool for the masses.

The first genetic dating services are already out there. At GenePartner in Switzerland, they claim to be able to match up love-starved singles on the basis of selected genes from their immune systems. A small handful of studies indicate that this genetic compatibility results in both better sex and healthier babies. You can also have your prospective boyfriend – fortunately, this only works for men – tested for whether he has an unfortunate genetic disposition for infidelity or for getting mixed up in bad relationships. If you already have children you can have them tested for whether they possess the genetic disposition for muscles more suited to speed-related or endurance sports.

In ten years, all newborns will routinely have their whole genome mapped and deciphered, say people in the know. And technological experts predict that, in a few years, a complete gene map with six billion bases will cost less than a baby carriage. What can these genome sequences be used for?

Jay Flatley, who heads major league genomics company Illumina, has said that “the limitations are sociological,” and, of course, that is correct. Social norms and political

legislation will dictate what we may do, and culture will dictate our demands and what we will actually do.

In China, ambitious – and well-to-do – parents take a step further and begin gene-testing their children in kindergarten in order to provide them with an optimal upbringing. Whether it is optimal for the child or the parents is a bit unclear, but it can all be done very practically at summer camp. At Chongqing Children's Palace, one part of the package is a test of eleven different genes that are supposed to provide an excellent picture of each child's potential. They send a little saliva to the Shanghai Biochip Corporation, which remits a statement about the child's intelligence, emotional control, memory and athletic abilities. The camp leaders supplement with interpretations pointing to possible career paths. Is there a tiny CEO in there, or should you rather push your child in the direction of an academic career or just accept that you are looking at a future accountant?

If you are a parent and nervous about not discovering and nurturing the native gifts of your little shaver, you can also contact the American startup My Gene Profile. In their promo videos, a mustachioed and slightly overweight guy explains that good parenting is all about directing your children toward success and happiness and that this is best done by identifying their abilities through a test of 40 genes. The test – or the interpretation you get from the company – will reveal what after-school activities you should sign your child up for and what education would provide the biggest pay-off for him.

It is the dream of a genetic horoscope – and, in the here-and-now, it is a pipe-dream. Both the Chinese children's camp and the American test-kit with accompanying books on child-rearing are humbug. Any serious geneticist would shake her head and call it con or quackery. No one knows of any set of individual genes that can be used to outline a human being's potential and point out the optimal direction of his or her life. That is pure fabrication. For now at least. But the fact that you can sell this sort of thing with great success says something about the status and role genes are about to have in our conception of ourselves. It also illustrates the hunger out there to be able to predict a life, to shape and optimize it according to our own designs.

But will it ever become a reality? Can the genome be a crystal ball that tells us how life will be? Might DNA be the path to self-knowledge and even a road to change?

I want to go in search of some answers. I want to know how it feels to have a close encounter with my DNA – this invisible, digital self that lies curled up like a fetus in every single cell of my body.