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Book Review

My Beautiful Genome
Lone Frank
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Shopping for a soft sweater and a comfy pair of genes

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Having recently finished watching the first season of *Forbrydelsen* (*The Killing)* I know something about Scandinavian knitwear. As the protagonist of this Danish TV thriller, Sarah Lund, doggedly solves a murder case, she is continuously huddling into a thick, cosy, snowflake sweater (there is even a website dedicated to this knitted garment). The traditional Scandinavian sweater is a useful image to have in mind when reading *My Beautiful Genome: Exposing our Genetic Future, One Quirk at a Time,* the most recent book by Danish science journalist Lone Frank, for it becomes a central metaphor within her argument:

> My genome is not a straitjacket but a soft sweater to fill and shape, to snuggle up and stretch out in. It is information I can work with and around, information that can grant me greater freedom to shape my life and my essence (p287).

Like many Scandinavian thrillers, *My Beautiful Genome* (previously published in Danish as *Mit Smukke Genome*) tells the story of a quest for truth. In this case it is Lone Frank's narrative of her search for information about her genetic past, present, and future. In many ways the straitjacket-sweater metaphor she uses is a clever one. The metaphor encapsulates the main message of the book - that genes are not our destiny but something we can "work

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with" – while also referring to her search for traces of genetic associations that explain her own family history of depression.

Lone Frank's father often told her that while she had many "trophies on the shelves" (p6) in the genetics department, she did inherit some "bad" genes from both her parents in regards to depression. Describing herself as an "incurable melancholic" (p207), Frank details an "unbroken line" of depression in her family. Her great-grandfather killed himself, his daughter (her grandmother) almost had a lobotomy, her mother suffered from depression, her father was "manic-depressive" and attempted suicide twice, and her brother has depression too. Counting both sides, Frank declares, her family boasts three successful suicides. We learn much of this family medical history in the opening pages of the book, during the recounting of an interview conducted by a behavioural genetics researcher:

> 'Have any of your first-degree relatives had any mental health problems?' 'Yes' I say without hesitation. I'm asked to identify which ones. 'All of them.' [The researcher] mumbles to herself, leafing through her papers, confused. 'All of them? Okay, okay. Where do we start?' (p3).

It is difficult to know where to start looking for answers in the world of psychiatric genetics. Although many psychiatric illnesses have been considered inheritable since classification, replicated research demonstrating significant genetic markers for diseases such as depression has been sparse. Just as straitjackets were used as a technology to cope with, and control, the unknown and feared aspects of mental illness, so too is genetic technology being used in an attempt to deal with the unknown. This remains a controversial area of research within psychiatry, and medicine more broadly. The recent move that some companies have made to advertise, or sell, genetic testing online directly to the public for diseases such as schizophrenia, bipolar disorder and autism, is contentious.

While dipping her toes into the controversies of psychiatric genetics, Lone Frank focuses more doggedly on the many avenues available to her to find out about her own genetic predisposition to depression and other traits and illnesses. The lengths Frank goes to in this search are impressive. She undertakes genome sequencing and personality tests for a Copenhagen University Hospital research project examining the connection between specific genes and depression. She is tested by Icelandic genetic testing company deCODEme and mines her raw data for genetic associations found in the scientific literature. She has blood tests in order to take part in research by a pharmaceutical company looking for biomarkers for mental illness. Along the way Frank also: signs up for a free 23andMe account which means that she can vote for which diseases and conditions the genetic testing company should research; takes an ancestry test offered by an American firm wanting to recruit Scandinavians; has a genetic test for breast cancer (which requires pestering and convincing the clinical geneticist to run a full BRCA sequence); and finally a test for genetic romantic compatibility. Frank pulls others, including her brother, into being tested to aid her genetic search, while she is pulled into the romantic matching test by a work colleague, having her (Frank's) boyfriend tested at the same time.

The comparative findings of these tests are interesting, for they provide very different, and sometimes contrasting, pictures of Lone Frank's psychiatric genetic makeup. Mining her deCODEme raw data reveals an increased risk of depression, while the personality test tells

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her that according to her neuroticism score she is "not particularly inclined towards depression" (p206). Later on her blood biomarkers put her "solidly in the group of depressed research subjects", while the genetic analysis run by the Copenhagen University Hospital tells her that she has two short variants of the SERT gene (responsible for serotonin transportation), findings which show a particular vulnerability to depression in association with "unfortunate life circumstances" (p219). The test also shows that she has a double dose of the "worrier" variant of the COMT gene, variants of the BDNF gene which make her sensitive to stress and two copies of a less efficient MAOA variant which predisposes women to depression. The university research results seem to be the most reliable findings for Lone – she throws her pen on the table when hearing the news: "So my damned recurring depressions don't just come from nowhere" (p219). She recognises the uncertainty of these findings but nonetheless considers herself a "pitiful loser in the genetic lottery" (p223). Interestingly, among all of these risks, inclinations, vulnerabilities and dispositions, the details of Lone Frank's experience of actually living with depression is dealt with lightly. Similarly, only one visit to her doctor is discussed in the book, and that visit is made in order to have some blood taken for the pharmaceutical research, while a prescription for antidepressants is renewed on the side. What seems to be much more fascinating for the author is the information she can find about depression inscribed in her amino acids.

The personal genetic testing narrative running throughout *My Beautiful Genome* is also a vehicle for Frank to discuss the current state of genetics. This is not Frank's first exercise in using her "self" as the central trope for exploring an area of science. Her previous book, *The Neurotourist: Postcards From the Edge of Brain Science,* examined the world of neuroscience while she underwent a series of cognitive tests, hormone tests and brain scanning.

In *My Beautiful Genome* we meet the familiar characters from any genetic detective story: James Watson, with whom Frank talks about the importance of psychiatric genetics and the need to publish more genomes on the internet; Kári Stefánsson, deCODEme's founder, who comes across as an annoyingly perfect genetic specimen; "elflike" and likeable Linda Avey, co-founder of 23andMe; and George Church from the Personal Genome Project. We also meet other less public characters on the genetic scene, such as the founders of Promethease (a free bioinformatics platform which allows users to learn more about their genotype), bloggers, epidemiologists and molecular scientists.

Little is revealed in many of Frank's interviews with famous characters beyond their public persona. Occasionally however an interview might reveal what is not made especially explicit in companies' mission statements. When Frank comments to Linda Avey that 23andMe has been compared, not admiringly, to Facebook, Avey pats her on the arm and says that "'The 'Facebook' format is quite deliberate', designed to encourage information sharing among users" (p121). Avey discusses one of the grand visions of 23andMe:

> We see ourselves as creating a sort of ecosystem of patients and users. People who stay with us on the website, who keep up with the developments and continue to enter in their data as they gradually get older. Can you see it? These groups – or cohorts – have built-in opportunities for conducting long-term studies that run for years. Studies that you cannot scrape together the money or the research subjects for today (p123).

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This is an ambitious ethos which is embedded, without being explicit, in 23andMe webpages, as the company tries to garner greater involvement in their self-proclaimed "Research Revolution", the democratic potential of which is not as straightforward as Avey would have it appear.

Lone Frank is at her best when she is examining the process of genetic testing, as she describes her own experiences of being tested. There is a great account of what fun it was to receive the deCODEme swabbing material in the mail, scrape her cheek and send the sample back to Reykjavik for analysis. The fun dissipates when she receives her results, in a hotel room, alone. Frank opens a can of beer for company. She feels certain that the test is going to report a high risk of breast cancer and keeps her eyes closed, long after she has clicked on the results. Finding out that she has a lower than average risk, she feels "as if a very old, hissing pressure deep inside [her] body quickly seeps out and floats away" (p77). She pores over the rest of her results, well into the long Icelandic night, later digging into her raw data over a series of late evenings on sites like Promethease. The uncertainty, fear and waiting involved in genetic testing is captured well in an anxious series of paragraphs where Frank describes waiting for her breast cancer gene sequencing results and experiencing diarrhoea all weekend.

Another strong aspect of the book is the science. As a science journalist, and being a biologist by training, Frank discusses the science well. When she uses jargon, she explains it. The book is very accessible, and would undoubtedly be of interest to those who want to learn more about genetic research. There is mention of many of the latest developments in genetic science: gene splicing, genetic engineering, the Human Genome Project, "snips" (or SNPs - single nucleotide polymorphisms), genomewide association studies and direct-to-consumer genetic testing (all in chapter one); paternity tests, ancestry tests, the ambitious genographic project (chapter two); 23andMe's Research Revolution, "genome bloggers" and others publishing their genetic profiles on the internet (chapter four); eugenics, schizophrenia twin studies, behavioural genetics, genetics x environment research, the connection between genetics and brain imaging (chapter five); personality research (chapter six); epigenetics (chapter seven); and finally genetic dating services, pre-implantation diagnostics and designer babies (chapter eight).

Just as readable as the 'genetics 101' sections are Frank's discussions of genetic research. Some parts of *My Beautiful Genome* read like a bibliography that has come to life; research from genomewide association studies to metanalyses published in *American Journal of Human Genetics*, *Nature* and *Molecular Psychiatry* become interesting and personalised. She uses clothing and interior decoration to give personality to the clinicians and scientists who have written these articles, picturing them in their offices with grey leather Arne Jacobsen chairs or in a cosy suburban kitchen with freshly baked brownies on the table.

Alas, if only she breathed the same kind of life into her biography as she does her bibliography. While Frank does offer us threads of genealogy - nostalgic moments with grandparents, sepia-toned photographs, memories of ancestors' illnesses and times with her father – her book is missing a richer sense of her own personal history, especially in relation to her experience of depression. What was it like to grow up in a family of "depressives" for

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example? What was she like as a teenager, a young adult, a science PhD? How has living in Denmark shaped her health and healthcare experiences? Frank claims that she wants to understand how the "accidents of biology" have shaped her life, her opportunities, her limitations, yet provides the reader with only very few glimpses into that life, those opportunities and limitations. While she does not claim to be writing an autobiography, the absence of her personal history nonetheless works to privilege a genetic view of her life story.

It is the few enticing glimpses into her biography which we are granted - her ability to deal with newspaper deadlines, a shoplifting incident - which make me want to know more, as I search for a less atomised understanding of this interesting woman and a more complex understanding of how genetics interplay with other aspects of her life. *My Beautiful Geno*me is personal, but mostly at the molecular level. Frank's story is so *biological*. When she talks about her interest in the human being as an organism, she does not refer here to an individual living in a rich social environment as an anthropologist or geographer might, but rather to the "microscopic processes unfolding" within us (p5). Even the "godfather of genetics", James Watson, admits in an interview with Frank that genetics are not central to his understanding of self. In response to her question about how knowing his genome has affected him, he replies "to be honest, I don't think much about it" (p17).

Anthropological and sociological research has shown that individuals often weave genetic information into their own pre-existing stories of relatedness and risk. Kerr and colleagues found in their research that the public had an experientially based knowledge of genetics, threading genetic information into everyday understanding of kinship[2]. In their study of Alzheimer's disease genetics, Lock and her colleagues found that genetic knowledge rarely usurped other forms of understanding, but was rather nested into previously held ideas[3]. Cox and McKellin suggest that the relevance of genetic risk to individuals is fluid and contingent, with information given higher relevance at certain critical junctures and at other times much less important[4]. Genetic information does not stand apart from other notions of inheritance and biography but rather becomes embedded into the complex ways we understand connections of relatedness and perceptions of risk.

Lone Frank is a science journalist, and good at explaining scientific matters for a broad audience, but less good at critically examining the "genetic supermarket" (p34) that she has entered. This is an aspect of the story that would be more prevalent in an anthropological or sociological account of genetic testing. Frank rarely criticises the commercial developments she documents and engages with, instead attempting neutrality, relying on others' critiques and letting her characters to speak in a way which does not implicate themselves.

There is also throughout the book an uncritical undercurrent of celebration of developments in genetic testing. Frank adopts industry words like "revolution" (p8), highlighting what she views as democratic ("genetic tests can be bought in supermarkets and pharmacies, tens of thousands of people around the world are getting acquainted with their genetic information by *using* it" (p286)), progressive ("in the next ten years, all newborns will routinely have their genome mapped" (p8)) and utopian ("presently, we're in the Wild West of personal genetic services – young, exciting, and full of golden opportunities" (p34)). According to *My Beautiful Genome* technological advance is inevitable, so we just need to engage with these technologies and enjoy the ride.

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This technological drive may in fact be at the heart of Lone Frank's quest, which could be seen as a search not only for genetic truth, but also to understand herself through new technologies and gadgets, whether they are related to genetics or to neuroscience. During a break in proceedings at a Human Genetics conference, Frank describes "standing in a corner feeling embarrassed" by her "passé SNP profile from deCODEme. It almost feels like I'm carrying around a chunky first-generation brick of a Nokia, while everyone else is watching videos on their iPhone 4s" (p138). Instead she wants to be part of the "in-crowd" (p139). How much of this trendiness drives other consumers of direct-to-consumer genetic testing? In their study of early adopters of direct-to-consumer genetic testing (half of whom, like Frank, worked in a field related to science), Michelle McGowan and colleagues showed that many of their participants viewed themselves as early adopters of new technologies more generally, and that this was the reason they wanted to try genetic testing[5]. *My Beautiful Genome* is situated very much within this context of technoscience/medical consumerism, with Lone Frank becoming a poster girl for consumer genomics.

Frank does recognise that not everyone may want to be part of this particular in-crowd. She wonders during a conference break, rather patronisingly, whether discussion about microbiomics and next generation sequencing would interest the girl serving the croissants. Nonetheless Frank writes with an underlying assumption that her audience will be those who also want to be in the in-crowd, or at the very least are interested in developments in genetic science.

Although *My Beautiful Genome* does not sit neatly within the illness narrative genre (indeed, as previously discussed, her own experience of depression is barely mentioned), it could certainly be read as a quest narrative[6]. Quest narratives have been criticised for being too neat, detailing clean transformation through discovery[7]. While Frank may engage in some wrapping-up towards the end of her book - concluding that she has terrible genes but can view these positively and make changes in her life in order to optimise her chances - her narrative doesn't suffer wholly from linear completeness. Rather, her story shows that psychiatric genetics, behaviour genetics and genetic testing are all imbued with some degree of uncertainty.

Perhaps the book could be considered part of another evolving sub-genre in literature, which may sit alongside the illness narratives, a kind of pre-illness narrative mixing autobiography with science journalism; a genre I would describe as auto-biology. Auto-biology is a term which possibly captures personal narratives, such as Frank's, which are all biology; stories told from a "molecular gaze"[8] where one's story centres around bundles of neurons or ribonucleic acid and the array of technologies tied up with understanding the body at this level. There is room for further scholarly analysis of these narratives, and the ways in which they shed light on how people think about science, as well as disease categories and other aspects of health and illness.

Having a background in medical science I can certainly see the appeal of this kind of exploring and writing. Yet I also yearn for more biography with my biology. I want to know how genetics becomes stitched into other ways of knowing and experiencing the world. In many ways it is ironic that Frank uses the loose sweater as a metaphor, one which could be

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seen to refer to epigenetics and the way the environment shapes genetic expression. Although in using this metaphor Frank is suggesting that she challenges a reductionist view in genetics, the material she presents and the assumptions she makes about the results that she receives suggest that she does indeed privilege genetics (p901), at least in this account. Her own environment so seldom appears in the story that her narrative reiterates new forms of genetic determinism, or "genetic enlightenment", which arguably predominate in the psychiatric genetic literature, where the role of the environment is merely rhetoric[9].

This does not mean that we need to discard the sweater metaphor completely however. A typical Scandinavian sweater, such as that worn by Sarah Lund, often has two different coloured yarns from different coloured sheep: one for the pattern, such as the snowflake, and another for the background. When knitting this kind of sweater the contrast yarn is pulled forward occasionally, to make the shards of the snowflake, but is otherwise kept behind the knitting. I like to think of genetic knowledge as the contrasting coloured wool which is knitted into an individual's sense of self-making, at particular moments, or junctures, in their lives, but which is generally kept in the background at many others. *My Beautiful Genome* is a well-written, readable, often witty narrative of a lone, intelligent, driven, technologically and genetically curious individual's journey into the world of personal genomics. I may be picky, or even nosey, but I would have liked a few more yarns to make the story just that little bit more personal.

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[2] Conrad, P. and J. Gabe. 1999. Introduction: sociological perspectives on the new genetics: An overview. In *Sociological Perspectives on the New Genetics*. P. Conrad and J. Gabe, eds. Oxford, Blackwell Publishers**:** 1 - 12.

[3] Lock, M., J. Freeman, et al. 2006. When it runs in the family: Putting susceptibility genes in perspective. *Public Understanding of Science***,** 15(3): 277-300.

[4] Cox, S. M. and W. McKellin. 1999. 'There's this thing in our family': Predictive testing and the construction of risk for Hutington Disease. *Sociology of Health & Illness*, 21(5): 622 - 646.

[5] McGowan, M. L., J. R. Fishman, et al. 2010. Personal genomics and individual identities: Motivations and moral imperatives of early users. *New Genetics and Society,* 29(3): 261 - 290.

[6] Frank, A. 1995. *The Wounded Storyteller*. Chicago, The University of Chicago Press.

[7] Thomas-MacLean, R. 2004. Understanding breast cancer stories via Frank's narrative types. *Social Science & Medicine* 58: 1647 – 1657.

[8] Rose, N. 2007. *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century*. Princeton, Princeton University Press.

[9] Hedgecoe, A. 2001. Schizophrenia and the Narrative of Enlightened Geneticization. *Social Studies of Science*, 31(6): 875-911.