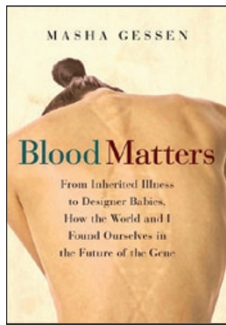


High anxiety



Blood Matters: From Inherited Illness to Designer Babies, How the World and I Found Ourselves in the Future of the Gene

By Masha Gessen

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Reviewed by Misha Angrist

Early on in *Blood Matters*, Moscow-based journalist Masha Gessen is having breakfast with a German acquaintance in Vienna. Gessen tells the woman about the book she's writing on life as a *BRCA1* mutation carrier at risk for early-onset breast cancer and mentions the genetic ancestry testing she's undergone in order to help her understand her family's origins and its history of breast and ovarian cancer. The German woman reacts with revulsion, undoubtedly born of growing up in a country with a terrifying eugenic past. "You are constructing biological identity out of anxiety!" she shouts. "Have you even read Foucault?" Gessen has indeed, but, as she explains to the reader with a wink and a shrug, "the facts were too bad for Foucault."

That vignette is telling. Throughout this remarkable hybrid of a book—part memoir, part science journalism, part narrative nonfiction—Gessen demonstrates both her independence and her willingness to tweak dogma, whether it comes from guilt-ridden postmodernists or didactic medical professionals. Her sometimes conflicting goals are to discover what is possible for herself as a breast cancer 'previvor' and to quench her reporter's compulsion to document and understand the genetic landscape as it shifts beneath her feet. Thus, she challenges a Harvard oncologist and a genetic counselor with data suggesting that maybe prophylactic mastectomy and oophorectomy are not such no-brainers after all, or at least not for her. She is still making use of her breasts to nurse her two-year-old, she says. As for her ovaries, she worries about the side effects of so-called surgical menopause, which may include increased risk of heart disease, high blood pressure, osteoporosis, cognitive disturbances and depression.

To her credit, Gessen gives equal consideration to the other side in the person of Henry Lynch, the eminent geneticist and oncologist who, during the 1960s, championed the heretical idea that some cancers were hereditary. Lynch was subsequently proved right and became passionate about the need for carriers of cancer-predisposing mutations to have prophylactic removal of their susceptible organs: colons, stomachs, ovaries, breasts. Gessen talks to a former patient who lost

three siblings to stomach cancer and, after being pestered by Lynch, underwent a life-saving gastrectomy. Obviously, these types of decisions are not mere abstractions for the 30-something Gessen, yet she never lapses into sentimentality.

Henry Lynch is just one of several larger-than-life iconoclasts appearing in *Blood Matters*. Another is Holmes Morton, the pediatrician who single-handedly brought medical attention to the Pennsylvania Amish and Mennonite communities afflicted with assorted recessively inherited diseases. Morton shows Gessen and the reader how genetics can be at once high-tech and homespun. While Morton's protégé Erik Puffenberger (disclosure: a grad-school colleague of mine) is carrying out homozygosity mapping on Affymetrix GeneChips inside the Lancaster, Pennsylvania-based barn/clinic, Morton is visiting with families and prescribing, say, valproic acid off-label to a child with type 1 spinal muscular atrophy. Geneticists, the late Victor McKusick reportedly said, are the last generalists in medicine; they must be prepared to address any organ system.

They are also often 'infovores'. It is interesting to note that in a time of regulatory and academic squeamishness about commercially available genome scans, Morton and his colleagues come down firmly on the side of genetic testing, even if it means testing children for adult-onset disorders. 'Knowledge is power' goes the crux of Morton's argument: genetic knowledge can enable quicker and more appropriate treatment, such as liver transplants in cases of congenital metabolic disorders like maple syrup urine disease. And where treatment is not possible, he says, a diagnosis may be, which itself might bring something like closure to parents. And failing that, detailed phenotyping may still benefit others with the same or similar diagnoses in the future. It has become fashionable to scoff at the terms 'personalized medicine' and 'gene therapy', but as Gessen shows, Holmes Morton is successfully practicing both.

Those looking for 'proceed with caution' messages and 'slippery slope' arguments about the specters of cloning and genetic engineering will likely be disappointed in *Blood Matters*. The title itself, to say nothing of the clunky subtitle, tips the author's hand. And certainly there are passages where Gessen seems to have been seduced by genetic determinism. When she says that "[W]e will go to our graves believing that it is a combination of letters in our genetic code that determines how we get there, and when," for example, it's hard not to roll one's eyes.

Other quibbles: I wish her detailed endnotes had been more explicitly linked to specific passages in the book. And finally, *Blood Matters* went to press before the 2007–2008 personal genomics frenzy, although of course that is hardly Gessen's fault.

In any case, such complaints are minor. I suspect most readers will simply take pleasure in the author's taut prose, skillfully woven narrative and insights into both herself and the ways in which genes do and do not shape our lives. Summarizing the views of preimplantation genetic diagnostic pioneers Yury Verlinsky and Anver Kuliev, Gessen writes, "There is no stopping the genetics future you say is so scary, because that future is already here." As a journalist and patient, Masha Gessen offers a unique and compelling guided tour of that future.

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