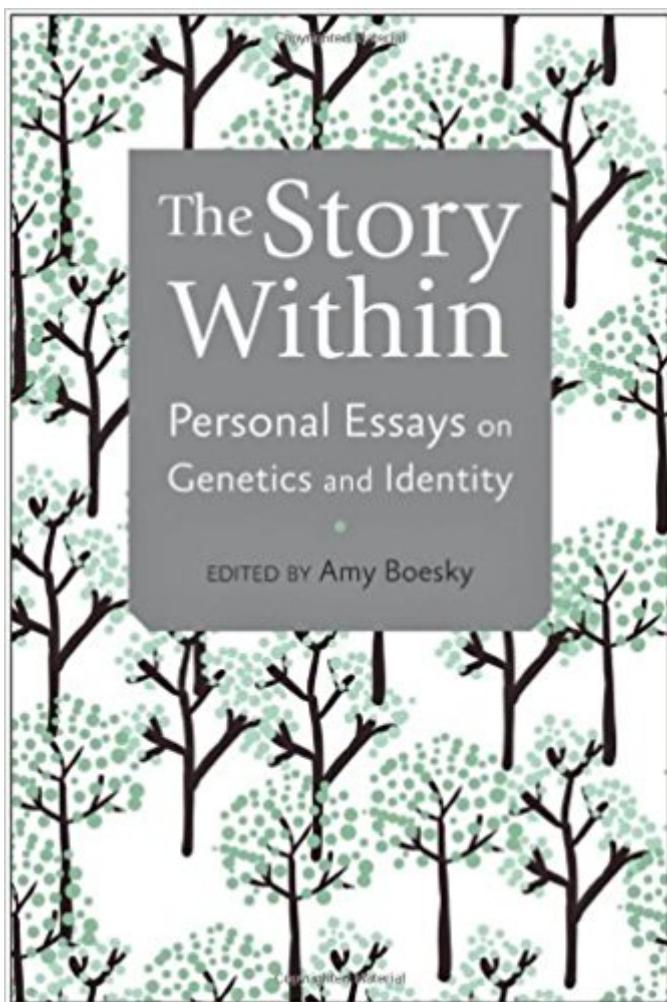


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# The Story Within: Personal Essays On Genetics And Identity



## Synopsis

The contributors to *The Story Within* share powerful experiences of living with genetic disorders. Their stories illustrate the complexities involved in making decisions about genetic diseases: whether to be tested, who to tell, whether to have children, and whether and how to treat children medically, if treatment is available. More broadly, they consider how genetic information shapes the ways we see ourselves, the world, and our actions within it. People affected by genetic disease respond to such choices in varied and personal ways. These writers reflect that breadth of response, yet they share the desire to challenge a restricted sense of what "health" is or whose life has value. They write hoping to expand conversations about genetics and identity—*to deepen debate and generate questions*. They or their families are affected by Huntington's disease, Alzheimer's disease, cancer, genetic deafness or blindness, schizophrenia, cystic fibrosis, Tay-Sachs, hypertrophic cardiomyopathy, fragile X, or Fanconi anemia. All of their stories remind us that genetic health is complicated, dynamic, and above all, deeply personal.

Contributors: Misha Angrist, Amy Boesky, Kelly Cupo, Michael Downing, Clare Dunsford, Mara Faulkner, Christine Kehl O'Hagan, Charlie Pierce, Kate Preskenis, Emily Rapp, Jennifer Rosner, Joanna Rudnick, Anabel Stenzel (deceased), Isabel Stenzel Byrnes, Laurie Strongin, Patrick Tracey, Alice Wexler

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## Customer Reviews

"A compelling collection of essays that address the experiences of many who have genetically

based illnesses... These pieces can comfort those in similar situations; inform friends, relatives, and caregivers; enlighten health providers; and help us all better understand how others experience the world in which we live. VERDICT Recommended for those who are touched by genetic disorders or are interested in health in the modern world." (Library Journal)"If there were an All-Star Team for memoirists struggling with genetic misfortune... The Story Within would surely be it." (Patrick Tracey PsychCentral)"This unique collection by a star cast of authors meditates on the complex relationship between identity and genetics. The essays are innovative literary engagements with the difficult philosophical and emotional issues raised by particular genetic inheritances. The authors cover a variety of genetic conditions, with varying levels and kinds of genetic risks and potential medical interventions, ranging from hereditary breast cancer to Huntington's disease and more." (Alexandra Stern, University of Michigan, author of *Telling Genes: The Story of Genetic Counseling in America*)"An important book... Amy Boesky's essay collection *The Story Within* exposes the ways we become self through our bodies and our kin. Studying genetic disorders that run in families illuminates an intimate aspect of identity. Choosing to read one's future in genetic code even when one is well is chilling as it is freeing. Boesky ushers in a new frontier of biological, autobiographical, and existential recognition, daring her readers to accompany her and her authors toward the light of knowing." (Rita Charon, M.D., Ph.D., Program in Narrative Medicine at Columbia University, author of *Narrative Medicine: Honoring the Stories of Illness*)"Thought provoking, moving and extremely interesting." (Jane Brown Nursing Times)"For those who have traveled a similar path and who have faced genetic illnesses, these stories can be a source of comfort. These stories can also help inform and educate and generate much needed dialogue about health and body norms. The narratives in *The Story Within* are a reminder that every life has value." (Dena Hurst Metapsychology)" The Story Within is a true success of a collection. With joy, rigor, and respect, it strives to reconcile something like the original (one-of-a-kind) and the originator (universal), the literal (DNA) and the literary (collected essays). Original review below" (Adrien Guignard Gesnerus)" The Story Within est un collectif rÃƒÂ©ussi. Il s'Ã¢cefforce avec bonheur, rigueur et respect de concilier quelque chose comme l'Ã¢corignal (singulier) et l'Ã¢corinaire (universel), le littÃƒÂ©ral (de l'Ã¢ADN) et le littÃƒÂ©raire (des textes rÃƒÂ©unis)." (Adrien Guignard Gesnerus)"When medical students really feel that they understand genetics... let them read *The Story Within* and be brought down to earth with a bang. I know I was." (BioNews)

Amy Boesky is an associate professor of English at Boston College and author of *What We Have: A Memoir*.

I found this collection of essays about people with various genetic disorders very interesting. I have however, read three full length books by authors in the collection about their lives so that was somewhat disappointing. Great insights and thoughts about various disorders that most people never think about... I recommend it especially if you know someone with a genetic disorder, you will think differently after reading this book.

Personal essays on what we know and have experienced on passing down genetic mutations, genetic inheritance, about family decisions and outcomes. Very well done! A must read! Edited by Amy Boesky.

Female cancers run in Amy Boesky's family. After her mother and aunt died young, Boesky and her sister chose elective surgery to forestall their own early deaths, a decision with ramifications not only for themselves and their childbearing potential, but for daughters who face the same grim choices. This painful personal history led Boesky to organize this collection, wherein people facing genetic diseases discuss what their genes say about them. Many authors have spilled much ink over genetic science, and its medical and ethical implications for modern society. Less has been written about genetic patients' lived personal experience, and little has received widespread attention. Thus, many patients suffering inherited illnesses, and parents passing such illnesses to their children, feel needlessly isolated. This collection should alleviate that loneliness, laying foundations for a community of dialog surrounding genetics' costs and opportunities. We've long known genetics exists. People comment on which parent a child more resembles, and warn kids about illnesses running in families. But developing science makes absolute knowledge possible where once we had only probabilities. Alarmists bleat of genetic discrimination and eugenics, while optimists praise the dawning era of treatment and prevention. But Boesky's authors demonstrate the lived truth, for ordinary people, is more complex and subtle than that. Boesky divides her collection three ways. Her first section focuses on discovering genetic inheritance and science's broadening diagnostic capabilities. We've become increasingly able to identify Alzheimer's, cancer, Huntington's, and other illnesses long before symptoms manifest. Does knowing equal a death sentence? When must we test ourselves for difficult, debilitating genetic illnesses? Alice Wexler, whose sister discovered the Huntington's gene, makes a persuasive case that knowledge isn't necessarily "the truth." Her second section analyzes treatment. Genetic diseases that once spelled inevitable mortality, like cystic fibrosis or hypertrophic cardiomyopathy, are now survivable, if recognized early. But

treatments require not only solid science, but a welcoming community. Illnesses like schizophrenia, with its significant genetic component, never get treated, or even diagnosed, when surrounding cultures refuse to discuss them openly. We cannot treat what we cannot acknowledge. Finally, Boesky turns to inheritance. What does it mean to have children, knowing they'll inherit illnesses that have no cure, and may suffer physical pain or social stigma? Authors write about the difficulty of having children, knowing they'll inherit disabilities and terminal conditions. And in one of this collection's most heartrending essays, Laurie Strongin describes the painful decision to bear another child for the purpose of treating her dying firstborn. Essays span the ideological map. Many authors come from Jewish backgrounds, unsurprisingly, since Jewish heritage has many diagnosed genetic anomalies. But one of this collection's most hopeful essays comes from Mara Faulkner, who has learned much about survival and perseverance from her life in a Benedictine order. Authors are rich and poor, theist and skeptic, liberal and conservative, educated and self-taught. Their experience with genetic illness, not ideology, binds them. Despite this collection's scientific underpinnings, not every essay approaches its subject equally. Misha Angrist, a working genetic scientist, and journalists like Charlie Pierce and Patrick Tracey, approach their subjects with appropriate precision, and though they don't do "dispassion," they certainly emphasize the facts. But Emily Rapp, Michael Downing, and others have little patience for unbiased detachment, spotlighting individual experience. Kelly Cupo most embodies this latter trend, eschewing science altogether. This collection's one misfire comes in Joanna Rudnick's essay about her struggles with BRCA, a female cancer gene. Basically, it isn't an essay; Amy Boesky interviews Rudnick about her efforts making a PBS documentary about BRCA. That documentary sounds interesting, but the interview feels very Entertainment Weekly-ish. Editor Boesky, who has BRCA herself, returns to this gene as the foundation of her interest, but this article feels misplaced and intrusive. Boesky's best essays strike a balance between objective science and workaday participation. Much as we like the idea of knowable reality, reality exists in the tension where we lack knowledge, but must act. And that's what Boesky's authors do: they act. They get tested and seek treatment, or embrace unknowing for solid, defensible reasons. Nobody here is a mere passenger on life's currents; they take command. Where science treats in testable knowledge, Boesky's authors offer lived experience, with its sloppy, chaotic tendencies in domains where nobody's ordeal exactly repeats anybody else's. Everybody facing genetic illness must reinvent the wheel. While this reality seems imposing, and we water our garden with tears, this collection reassures us that real humans have the ability to face that new reality with dignity and triumph.

This is an uneven but interesting collection of essays by people affected by genetic disorders. I found it thought-provoking and challenging. With the advances in genetic screening, science is merging with morality in ways never anticipated. For instance do you, as the woman may very likely possess the cancer gene, amputate presumably healthy tissue without getting tested? If you get tested, how do the results impact your life and choices and why? A range of disorders are discussed, including schizophrenia, cystic fibrosis, cancer, deafness and blindness. As there are sixteen different authors, the essays are not equally successful. Yet each puts a human face on science. Recommended

There's nothing I enjoy more than a first-person essay, so I was looking forward to reading this book. This book contains sixteen essays from contributors whose lives have been touched by the specter of genetic disorders. Some writers tell of suffering from disease or watching family members suffer, while others speak of the possibility of disease looming and what that means for their state of mind and the decisions they make. Unfortunately, for the most part I found the essays an unsuccessful mix of story and study. It's the personal narrative that interests me most, and in most of the essays it is overshadowed by lengthy discussions of a more scholarly nature. Only a few essays held my interest ( "Why Would You Be Wanting to Know" Not Talking about Schizophrenia in Ireland; String Theory, or How One Family Listens through Deafness; What If), and I think it's because in these essays, the elements of story and study were well balanced. A person for whom genetic disease is a more personal and urgent matter would appreciate the scientific side of these essays more than I did. As examples of collections of essays having a connection to health matters that I did enjoy, I would recommend two anthologies edited by Lee Gutkind, "Becoming a Doctor: From Student to Specialist, Doctor-Writers Share Their Experiences" and "I Wasn't Strong Like This When I Started Out: True Stories of Becoming a Nurse. His earlier anthology, "At the End of Life: True Stories About How We Die, is also worth reading, although I found the stories in that book somewhat one-note (hospitals bad, hospice good).

Amy Boesky has put together an excellent group of essays about genetic disorders from 15 different contributors, all dealing with issues such as alzheimer's, cancer, deafness, schizophrenia and more. The book is a bit hard to follow, but the decisions involved with genetic disorders are complex, so in that regard it's good for the reader to think about them.. to get tested or not, who to tell, whether to have kids, etc. Patrick Tracey's essay, "WHY WOULD YOU BE WANTIN' TO KNOW?" Not talking about schizophrenia in Ireland is maybe the best in the book. A good and worthwhile read

for anyone wanting to think more deeply on genetics and how we as a society deal with it's varying effects.

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