



The Story Within

Amy Boesky

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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, Isabel Stenzel Byrnes, Laurie Strongin, Patrick Tracey, Alice Wexler

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Joshua Stamper:

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John Merritt:

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