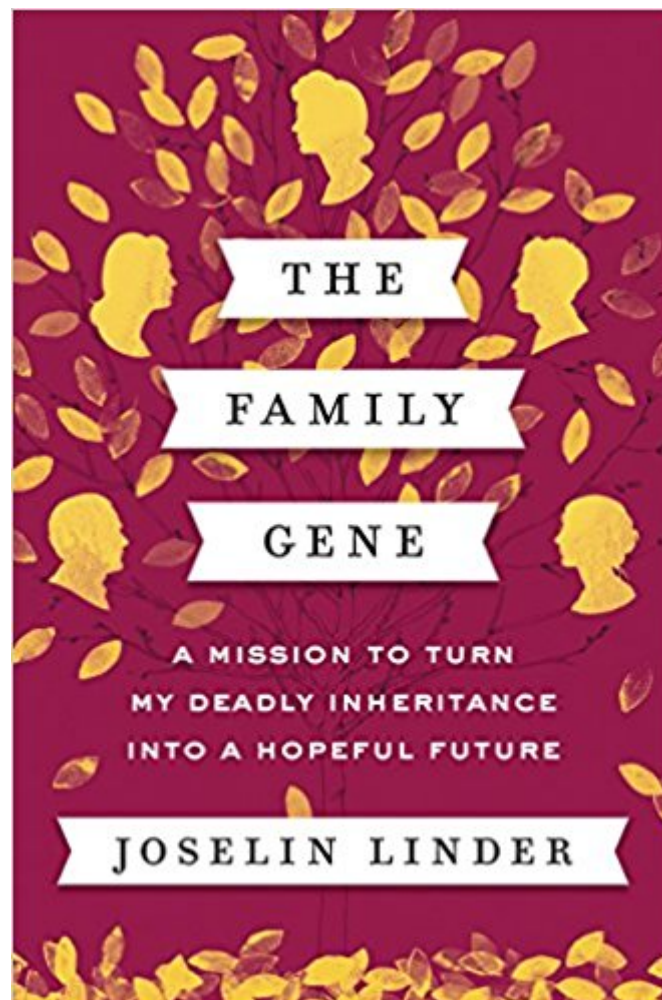




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The Family Gene: A Mission To Turn My Deadly Inheritance Into A Hopeful Future



Synopsis

A riveting medical mystery about a young woman's quest to uncover the truth about her likely fatal genetic disorder that opens a window onto the exploding field of genomic medicine. When Joselin Linder was in her twenties her legs suddenly started to swell. After years of misdiagnoses, doctors discovered a deadly blockage in her liver. Struggling to find an explanation for her unusual condition, Joselin compared the medical chart of her father—who had died from a mysterious disease, ten years prior—with that of an uncle who had died under similarly strange circumstances. Delving further into the past, she discovered that her great-grandmother had displayed symptoms similar to hers before her death. Clearly, this was more than a fluke. Setting out to build a more complete picture of the illness that haunted her family, Joselin approached Dr. Christine Seidman, the head of a group of world-class genetic researchers at Harvard Medical School, for help. Dr. Seidman had been working on her family's case for twenty years and had finally confirmed that fourteen of Joselin's relatives carried something called a private mutation—meaning that they were the first known people to experience the baffling symptoms of a brand new genetic mutation. Here, Joselin tells the story of their gene: the lives it claimed and the future of genomic medicine with the potential to save those that remain. Digging into family records and medical history, conducting interviews with relatives and friends, and reflecting on her own experiences with the Harvard doctor, Joselin pieces together the lineage of this deadly gene to write a gripping and unforgettable exploration of family, history, and love. A compelling chronicle of survival and perseverance, *The Family Gene* is an important story of a young woman reckoning with her father's death, her own mortality, and her ethical obligations to herself and those closest to her.

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Customer Reviews

“Surprisingly buoyant . . . Describing how it feels to face the likelihood of a shortened life-including her conflicted desire to be a mother, despite the risks for any child-Linder reminds us that hope isn’t the same thing as truth.” (New Yorker) “The Family Gene [is] both congenial and engaging, despite the long shadow of a broken gene.” (New York Times Book Review) “Linder’s memoir is a personal tale of loss, illness, ethical dilemmas and emotional fallout. Some of the details are harrowing. But Linder tells her story in a smart, wry voice devoid of self-pity.” (Chicago Tribune) “Crisply written, deeply informed. . . . Linder captures the dread and fatigue that accompanies such an odyssey. The Family Gene nails this truth in a clear, honest voice, an invaluable addition to the literature that dramatizes severe illness and its impact.” (Minneapolis Star Tribune) “Linder not only knows how to tell a compelling story but also how to use numbers to good effect and how to spell out complicated concepts.” | Her brutal honesty contributes to the power of this thoroughly researched chronicle of the quest to conquer chromosomal abnormalities.” (Booklist, Starred Review) “Moving and deft. . . . Linder expertly balances the serious and often tragic with an indefatigable charm and warmth. This book is a wonderful blend of reflections on coming of age, medicine, and what it means to live against all odds.” (Publishers Weekly (Starred Review)) “Linder’s narrative is a combination of a fascinating medical detective story and an absorbing, powerfully written family chronicle. . . . She successfully integrates cutting-edge genetic research into her personal quest. (Kirkus) “[Linder] views her future with measured optimism.” | Genealogists and readers interested in popular medicine may find this book more relatable than Alice Wexler’s Mapping Fate.” (Library Journal) “The science is enthralling, the narrative’s race-against-the-clock tension is nail-biting, but at its core, this book is about the remarkable bond of family—and curse and gift of inheritance.” (Susannah Cahalan, author of Brain on Fire) “A riveting story of a family, a disease, genetics, and the eternal path of living and dying we all walk. Intimate and instructive, immeasurably wise, Linder’s big-hearted and intelligent story of her tenacious search for answers to her family’s singular disease will leave you breathless.” (Jennifer Gilmore, author of Golden

Country)“Linder’s writing is magnetic. She weaves this deeply personal story with fascinating scientific discoveries—somehow leaving us hopeful, heartbroken, and inspired all in the same breath. (Abby Sher, author of *Amen, Amen, Amen*)“The Family Gene is both a riveting medical mystery and a heart-wrenching family memoir. With compassion and humor, Joselin Linder keeps us turning the pages until we fully share her stunning insight: that genetics is equal parts science and love. (Andrew Blum, author of *Tubes*)“Three of the most powerful forces in life are family, love and science. Joselin Linder, through a combination of the fates, found herself in a position to tell a first-person tale of how those forces can intersect. (Bob Greene, author of *Once Upon a Town: The Miracle of the North Platte Canteen*)“This unique book is at once a compelling mystery, a moving personal story, and a fascinating exploration of cutting-edge science. Scary and hopeful, perceptive and empathetic, it will give you new perspective on your own life choices and those of the people you love. (Rachel Fershleiser, editor of *Not Quite What I Was Planning*)

A GRIPPING MEDICAL MYSTERY THAT OPENS A WINDOW ONTO THE EXPLODING FIELD OF GENOMIC MEDICINEWhen Joselin Linder was in her twenties her legs suddenly started to swell. After years of misdiagnoses, doctors discovered a deadly blockage in her liver. Struggling to find an explanation for her unusual condition, Linder compared the medical chart of her father—who had died from a mysterious disease, ten years prior—with that of an uncle who had died under similarly strange circumstances. Delving further into the past, she discovered that her great-grandmother had displayed symptoms similar to hers before her death. Clearly, Linder’s illness was more than a fluke. Setting out to build a more complete picture of the sickness that haunted her family, Linder approached Dr. Christine Seidman, the head of a group of world-class genetic researchers at Harvard Medical School, for help. Dr. Seidman had been working on her family’s case for twenty years and had finally confirmed that fourteen of Linder’s relatives carried something called a private mutation—meaning that they were the first known people to experience the baffling symptoms of a brand new genetic variant. Here, Linder tells the story of their gene: the lives it claimed and the lives that advances in genomic medicine still have the potential to save. Digging into family records and medical history, conducting interviews with relatives and friends, and reflecting on her own experiences with Dr. Seidman, Linder pieces together the lineage of this deadly gene to write a gripping and unforgettable exploration of family, history, and love. A compelling chronicle of survival and perseverance, *The Family Gene* is an important story of a young woman reckoning with her

father's death, her own mortality, and her ethical obligations to herself and those closest to her.

Joselin Linder's book, "The Family Gene: A Mission to Turn My Deadly Inheritance into a Hopeful Future", is a combination science book and coming of age story. Now in her mid-30's, Joselin has seen several members of her father's family - including her father - die from an untreatable disease that also defied classification. The disease was spread among several generations of the Linder family. While working with doctors and geneticists in Boston, a genome was discovered which made testing for the gene easy to determine what family members would be affected. Genetic investigation has come incredibly far in the last 30 years. I simply don't have the scientific vocabulary needed to write the technical things in this review. But Linder does a good job at explaining and defining; I figure I understood about 3/4 of what she wrote. Linder writes about the lives of the her paternal family and explains how the disease - still unnamed - began with a genetic mutation in the body of her paternal great-grandmother and was distributed down the proverbial genetic family ladder. Back to the issue of genetic testing. There are actually two issues at work. Would you want to know if you hold the prospect of contracting Huntington's Disease or the disease the Linder family has? The implications are astounding to the way you live your life. The other testing is that of a fetus to see if he or she carries the gene of the disease. And if the tests showed you were pregnant with a baby with the disease, would you have an abortion? Linder writes about the genetic testing routinely done these days of prospective parents. Joselin Linder's book is well-written and I learned a lot. I could have done without most of the coming-of-age parts but I guess that living under the scythe of life or death made her decisions and thoughts more unique than the average 30 year old.

Reading a book about genes, biology, anatomy, etc would normally be nowhere near my must read list, but this book is no boring science read. It's a mystery, a love story, and a family album. Through the heartbreak there is hope. The author weaves humor throughout the story and tells it beautifully. I'll recommend to everyone.

Beautiful, thoughtful book. Deeply moving, often witty, totally engrossing and thoroughly enjoyable to read. Truly a wonderful book, I highly recommend it.

From beginning to end, a great read.

The author poignantly recounts her family's story of discovering a fatal genetic disease. She admits her own foibles and denials even as she continues to lay out the details. She includes details about genetics and how amazing advances have made. Fortunately there are doctors who take an interest in studying this abnormal disease and pursue it for years.

This is an extraordinary story and an incredibly well-written page turner of a memoir. Combining both the personal and scientific, the author shares her family's grueling, heartbreaking search for a cure to their undiagnosed genetic illness alongside the Harvard scientists doing everything they can to identify it and save the author, her extended family members, and their future offspring. It was hard to put down and I highly recommend it to anyone interested in a gripping personal story as well as a medical mystery. I laughed, I cried, I cheered. What more can you ask for?!

What an incredible story! Joselin Linder tells it like it is with seriousness, yet with an incredible sense of humor woven into the words. Her explanations of the medical terminology is clear and precise with helpful metaphors to aid in the understanding. She, her family, and those close to her are amazing and brave souls! A wonderful read and hopefully a movie someday.

Loved this book! What an amazing story! This author's living tale is a page turner. It's heart warming and thought provoking. Medical terms are light and understandable. While this genetic story is rare, it's totally relatable. I am rooting for modern day science to help Joselin, her family, and us all.

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