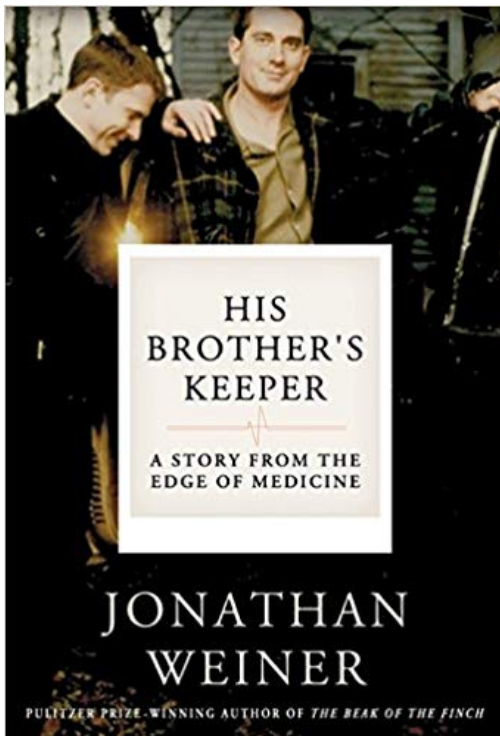


His Brother's Keeper: A Story from the Edge of Medicine *by* Jonathan Weiner



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From Jonathan Weiner, Pulitzer Prize-winning author of *The Beak of the Finch*, comes *His Brother's Keeper* -- the story of a young entrepreneur who gambles on the risky science of gene therapy to try to save his brother's life.

Stephen Heywood was twenty-nine years old when he learned that he was dying of ALS -- Lou Gehrig's disease. Almost overnight his older brother, Jamie, turned himself into a genetic engineer in a quixotic race to cure the incurable. *His Brother's Keeper* is a powerful account of their story, as they travel together to the edge of medicine.

The book brings home for all of us the hopes and fears of the new biology. In this dramatic and suspenseful narrative, Jonathan Weiner gives us a remarkable portrait of science and medicine today. We learn about gene therapy, stem cells, brain vaccines, and other novel treatments for such nerve-death diseases as ALS, Alzheimer's, and Parkinson's -- diseases that afflict millions, and touch the lives of many more.

It turns out that the author has a personal stake in the story as well. When he met the Heywood brothers, his own mother was dying of a rare nerve-death disease. The Heywoods' gene therapist offered to try to save her, too.

"The Heywoods' story taught me many things about the nature of healing in the new millennium," Weiner writes. "They also taught me about what has not changed since the time of the ancients and may never change as long as there are human beings -- about what Lucretius calls 'the ever-living wound of love.'"

"The Heywoods mean the whole story to me now: an allegory from the edge of medicine. A story to make us ask ourselves questions that we have to ask but do not want to ask. How much of life can we engineer? How much is permitted us?"

"What would you do to save your brother's life?"



Reviews of the **His Brother's Keeper: A Story from the Edge of Medicine** by Jonathan Weiner

Xor

Just as riveting as Time, Love, Memory and The Beak of the Finch and more personal, more riveting. Danskyleyn

I read a review of this book and instantly wanted to read it. It is a heartbreaking story of an amazing family and the sacrifices one brother makes for another. It is well researched and although science is one of the major stars here, the author makes it understandable to the lay person. It made me laugh and cry along with the family - the kind of book you save to read again. I will follow Steven's progress with care and keep this family in my heart for long after the book is finished.

Zeks Horde

great book! nice deliver!

Morad

Poor writing and a dull read. If this isn't absolutely necessary for you, don't buy it. There are better books about ALS out there.

Lightwind

Jonathan Weiner's His Brother Keeper" A Story from the Edge of Medicine, is the touching tale of two brothers, one with an incurable disease and the other who pushed the envelop to save him.

Amyotrophic lateral sclerosis (ALS), better known as Lou Gehrig's disease is a terminal, unrelenting medical condition that strikes seemingly random young adults and slowly takes away muscle control. With no known cure or even treatment, Steven and Jamie Heywood fell into this rare condition at a time when the promise of gene therapy was just beginning to take hold. In addition, the successful political advocacy of AIDS groups in the 90's encouraged others to take up the mantle of rare diseases and force the medical community to take notice.

Weiner concentrates mainly on Jamie who organized and cajoled researchers in an attempt to streamline treatment development. This was especially problematic due to high profile failures as well as significant ethical concerns about this brave new world approach. While Weiner concentrates mainly on Jamie, he provides snippets and insights into the whole family as well as his own family that was dealing with a related, but different medical condition with his mother. Weiner provides intimate details, along with the major storyline of the attempts to craft novel, but highly experimental therapies. His tale documents the broad impact of disease, not just on the patient, but the whole family as well as close friends.

Sadly, although the story is mainly concerned with the time frame around 2000, even 17 years later, little progress has been made towards curing or even treating ALS.

salivan

A couple of years ago I had a cancer scare. There was a growth in my kidney that the doctors said was either a dense cyst or a tumor. So I had to have a CAT scan every six months for a year in order to monitor the growth. If it stayed the same, I was OK. But if it expanded, cancer was the most likely diagnosis. Fortunately, it turned out to be a cyst. But I came away from that experience with the knowledge that things can go terribly wrong in my body even if I do everything right. How do you deal with such a worst-case scenario, and how far do you go for a cure?

So it was with Stephen, a healthy and active 29-year-old from a successful family of overachievers. One day, Stephen was unable to turn the key in the door of the house he had just finished remodeling. He dismissed it as fatigue, but his hand continued to weaken and other symptoms arose. Finally, he could no longer ignore signs that something was wrong. He was examined and given a terrible diagnosis: ALS (Lou Gehrig's Disease). His younger brother Jaime, an engineer with an entrepreneurial streak, immediately switched careers to genetic engineering and began a race against time to save Stephen. Jamie founded an ALS foundation and enlisted the aid of various medical and research experts to help him find a cure using gene therapy. As Stephen's health declined, the pressure to find a cure intensified, until the stress began to take its toll on everyone involved.

I was afraid that "His Brother's Keeper" would be a turgid read, but I was mistaken. Jonathan Weiner writes in a clear fashion, and has the ability to make complex subjects easy to comprehend. The author uses Stephen's saga as a gateway to the world of cutting-edge medicine, including cloning, gene therapy, and the use of stem cells. He also reveals the arcane world of drug development and testing in the United States. Not surprisingly, medical ethics also come into play, such as the right and wrong of profiting via seeking cures, and experimental drug trials on dying humans who have no other options. But most compelling was the personal story of a family rallying to the side of a terminally ill member. Mr. Weiner was not exempt from tragedy either, for he parallels Stephen's fight with his mother's decline from a rare neurological disorder. His account of the moment when he discovered she was "not Ponnie and...not my mother (p 220)" is perhaps one of the most disturbing passages I've ever read in a non-fiction book.

Despite its excellence, I would've liked two changes in "His Brother's Keeper." First, it seemed that Stephen was a cipher in his own story. He pops in and out of the proceedings at various stages of disability, and appears lost in the tornado of Jaime's quest, the author's personal struggles, and the medical discourses. Perhaps that was intentional, but knowing Stephen better would have made him a more compelling figure. Second, the book does not end with Stephen's inevitable death and its repercussions. I wanted the closure of finding out how Stephen and his family dealt with his passing and the aftermath. But even with these issues, "His Brother's Keeper" is a fascinating tale of one family's forced entry into a part of medicine that is almost science fiction in nature. Recommended.

Silverbrew

I just finished "His Brother's Keeper" and will not forget this family for a long time. This book is incredibly sad but it also shows the hope of a family trying to reverse the course of a terrible illness. It is a story of the turn of a new century, when there was hope in gene therapy, in internet start ups, in Dolly the sheep.

The characterization within this book was excellent. The people who stuck out for me were Jamie, his brother Stephen and Stephen's wife Wendy. Jamie is the epitome of the driven man. His energy pops off the pages. Stephen is the searcher, the world traveler and, as Weiner writes, the Gen-X "slacker." That is, until Stephen finds his calling in carpentry and is just as driven as his mechanical engineer/entrepreneur brother.

Wendy is introduced later in the narrative. She is by her boyfriend's (eventually husband's) side as he goes through the progression of the disease. Whether arguing with a neighbor or keeping a visage of hope for her husband, she is a valuable presence in Stephen's life and in this book.

The author Jonathan Weiner is part of the story as well. He is captivated by the Heywoods and readily acknowledges it. His own mother is ill, and, as a "science writer," he has both knowledge and hope for the promise of new therapies and cures. Weiner writes of medicine, of the Heywood brothers, wives and parents, of September eleventh (briefly), and primarily, of hope. Hope and family are at the heart of this sad story of the new millennium.

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