



His Brother's Keeper

By Jonathan Weiner
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Introduction

His Brother's Keeper is 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.

Questions for Discussion

1. What is Stephen's role in his own story?
2. Is Jamie a sympathetic character? Is there any moment in the book when your opinion of him changes?
3. On p. 259, Stephen tells Jonathan Weiner that he is "hooked." Do you think that the Author's degree of investiture in the Heywood story is affected by his mother's neurological disorder? How so and to what extent?
4. What are the parallels between Stephen's illness and that of Ponnies'?
5. Was Jamie's race worthwhile in the end? Do you feel that he should have used his time differently? Do you agree with Stephen's choices?
6. Do you think that Jonathan Weiner agrees with the experimental treatments being developed by Jamie and his team?
7. Is Jamie really struggling to be "his brother's keeper" or is his quest a means of avoiding the truth of Stephen's ALS?
8. Do you think that governmental agencies such as the FDA and the RAC should make greater exception in cases like Stephen's? Should regulatory criteria be the same in developing treatments for all diseases or do orphan diseases (like ALS and Lewy Body Dementia) require a more lenient approach?
9. **His Brother's Keeper** takes place during the last few years of the twentieth century. Has there been a change in public opinion regarding gene therapy since then? How do you feel about the fact that the Heywoods are a church going family, but also support gene therapy?
10. Jamie finds himself torn between altruism and entrepreneurship. Would there have been a benefit to selling his idea to "big pharma"? Do you agree that his struggle to find treatment for Stephen would have been regarded differently if he had chosen to profit from the research?

About the Author

Jonathan Weiner's books have won the Pulitzer Prize, the National Book Critics Circle Award, the *Los Angeles Times* Book Prize, and many other honors. While working on **His Brother's Keeper**, he was writer-in-residence at Rockefeller University. He lives in Bucks County, Pennsylvania, with his wife and their two sons.