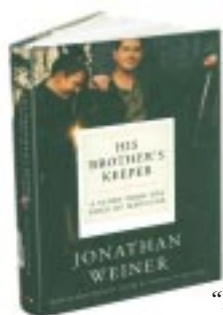


Deploying Science to Desperate Ends

IN THE SEARCH FOR CURES, HOW MUCH IS PERMISSIBLE? BY CLAIRE PANOSIAN DUNAVAN



**HIS BROTHER'S
KEEPER: A STORY
FROM THE EDGE
OF MEDICINE**

by Jonathan Weiner
HarperCollins, New York,
2004 [\$26.95]

*"Diseases desperate grown
By desperate appliances are relieved,
Or not all."*

—William Shakespeare, *Hamlet*

Not long ago I got an e-mail from Nikki. My high school friend-turned-lawyer now communicates solely by laptop, propped in an electric wheelchair, twitching her lip to activate her keyboard. She is fed through a stomach tube, and a ventilator breathes for her 24/7. If a fly lands on her face, she is powerless to brush it away. Nikki has amyotrophic lateral sclerosis, also known as ALS or Lou Gehrig's disease. So do 30,000 other Americans, of whom 8,000 die every year.

Stephen Heywood, a six-foot-three carpenter from Boston, was 28 when his motor neurons began to fail. The earliest clue was subtle: he lost his first arm wrestling match in years to his older brother, Jamie. Then he couldn't turn a key in the front door of a house he was restoring. A year later he stumbled and pitched headfirst down a stairway. ALS is nothing if not relentless.

Jonathan Weiner's latest book, *His Brother's Keeper*, is about ALS plus much more. Part biography, part autobiography, it deals with a family's journey into a previously unimaginable realm,

Gen X-er Jamie Heywood's desperate desire to use genetic and stem cell technology to turn the tide of Stephen's disease, the author's coming to terms with his own mother's agonizing decline from another form of nerve death, and the current era of "anything is possible now" science. Weiner won the Pulitzer Prize for his 1994 book about evolution, *The Beak of the Finch*. In *His Brother's Keeper*, his prose is just as graceful and steady but far more personal and revealing. Like his subjects, Weiner is also on a journey.

Clearly, a kinship links the author and the Heywood brothers. For one thing, they share eerily similar intellectual roots. Stephen and Jamie's father is a mechanical engineer on the faculty at the Massachusetts Institute of Technology (Jamie also graduated from M.I.T. with a degree from his dad's department). Jerome Weiner, Jonathan's father, is an engineering professor at Brown. In the course of the book, Weiner asks his father about Jamie's extreme makeover from high-tech entrepreneur to guerilla bioscientist. His father replies by likening genes, DNA and protein to any other system—a pulley, a circuit, an engine. At which point the writer adds dryly: if what has broken is nothing but a system made of molecules, engineers try to fix it.

Unfortunately, ALS is not that easily fixed. When Stephen was diagnosed in 1998, the only FDA-approved drug for the disease was a glutamate blocker (glutamate is a chemical that carries signals between the brain and the spinal cord but

also damages the nervous system when released in excess). Convinced that repairing the glutamate transporter protein system is a hopeful tactic for ALS sufferers, Jamie and his scientific collaborators Jeffrey Rothstein of Johns Hopkins University and Matt During of Jefferson Medical College plan to insert the corresponding gene in Stephen's cells. Until fate works against them, that is. A teenager with a rare metabolic disease dies after undergoing experimental gene therapy, Jamie's project is tabled, and During proceeds to plan B: injecting millions of stem cells into Stephen's spinal canal.

I longed to hear more from two voices throughout this otherwise fine and moving book. Over a 25-year career,



"THE HEYWOODS mean the whole story to me now," writes author Jonathan Weiner, "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?"

Robert Brown, the ALS specialist at Harvard Medical School who diagnosed Stephen, has led thousands of patients where no one wants to go: the edge of a cliff looking straight down. His perspective would have balanced Jamie's frantic race for a magic bullet. The other voice I missed was Stephen's. Not his matter-of-fact statements, which do weave through the narrative, but his inner thoughts. Was this omission dictated by Stephen himself or the author's delicacy, I wondered.

The 1990s—officially deemed “The Decade of the Brain”—did yield remarkable new facts about the human nervous system as well as breakthroughs in ways of reengineering cells. What is both poignant and telling is Jamie's (and possibly Weiner's) notion that science might, as a result, rescue ALS victims on a specific timetable. Medical miracles do not obey timetables, even in an era of quantum scientific leaps.

But there are other miracles in this book and in the lives of ALS patients. In 1999 Jamie Heywood launched a fledgling organization called the ALS Therapy Development Foundation. Today it is well funded and staffed, supporting a number of important research efforts. Stephen Heywood married and had a child, despite the inexorable progress of his disease. And Nikki, my dear friend, continues to engage with life: electronically overseeing her household; cheering husband, family and friends; attending her kids' school and sports events and a biweekly book club. In ALS, the triumph of the human spirit is the greatest miracle. *His Brother's Keeper* may focus on the promise of science, but the mystery of transcendence also speaks from its pages loud and clear. SM

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THE EDITORS RECOMMEND

MY FAMILY ALBUM: THIRTY YEARS OF PRIMATE PHOTOGRAPHY

by Frans de Waal. University of California Press, Berkeley, Calif., 2003, \$29.95.



“Human laughter derives from the primate's ‘play face.’ Not only do the human and ape expressions look alike—with half-open mouth and relaxed muscles around the eyes—the accompanying sounds, too, have much in common. In bonobos, laughter is a hoarse, rhythmic breathy sound heard especially during intense tickling matches. In the ... photo, a juvenile bonobo shows the ‘classic’ play face with the upper teeth covered.”

This excerpt is from a book of exceptional photographs and extended captions by de Waal, who is C. H. Candler Professor of Primate Behavior at Emory University and director of the Living Links Center at the Yerkes Primate Center in Atlanta.



THE BOOK NOBODY READ: CHASING THE REVOLUTIONS OF NICOLAUS COPERNICUS

by Owen Gingerich. Walker & Company, New York, 2004 (\$28)

In a 1959 best-selling history of astronomy, Arthur Koestler called Copernicus's *De revolutionibus* (which set forth the controversial view that the sun rather than the earth was at the center of the universe) “the book that nobody read.” Gingerich, then an astrophysicist at Harvard University, happened on a first edition from 1543 richly annotated by a well-known 16th-century astronomer. At least one person had read the book! His fascination with this find turned Gingerich into a full-time historian of science and, to prove Koestler wrong, sent him on a 30-year odyssey to examine every first edition he could track down. This is the story of that quest, in which Gingerich covered hundreds of thousands of miles, uncovered 276 first editions and showed that Koestler was, indeed, wrong. The marginal notes, especially in copies that had belonged to other astronomers, reveal

how much Copernicus's thesis was being debated by his contemporaries. Part detective thriller, part vivid historical biography, it's all fun.

All the books reviewed are available for purchase through www.sciam.com

