HIS BROTHER’S KEEPER: A Story from the Edge of Medicine

[by John M. Weiskopf]

Would you become your brother’s keeper? Or your sister’s? Your spouse’s? Maybe your mother’s or father’s keeper as they grow old? Would you commit yourself to care for a terminally ill family member who, by all medical standards, has an incurable disease, a disease that will rip you from your livelihood, place you and your family in enormous debt, may linger for years, destroying your dreams, your hopes, your very soul? Could you watch your beloved deteriorate down to a skeleton, unable to hold his or her bobbling head up, barely able to barely speak or even remember you? Could you do it? Would you? How far would you go?

In Jonathan Weiner’s recently published His Brother’s Keeper: A Story From the Edge of Medicine, the Pulitzer-Prize winning author tells an incredible story of two brothers in the Heywood family, two brothers linked more than just by blood, but by a deep struggle to stave off the horrible, inevitable effects, and eventual death, of one of the brothers from ALS, more popularly known as Lou Gehrig’s disease. It killed Lou Gehrig and will kill scientist Stephen Hawking. His Brother’s Keeper is a story reminiscent of the great brother stories of Rich Man, Poor Man, Cain and Abel, the Wright Brothers, and the dramatic political arena of the Kennedys: Joseph, John, Robert, and Teddy.

In 1994, Jonathan Weiner wrote The Beak of the Finch, for which he won the Pulitzer Prize. The Beak of the Finch is brilliantly and elegantly written, a page turner. It is the groundbreaking story of the scientific research conducted by two scientists, Peter and Rosemary Grant, who spent 20 years showing that Charles Darwin himself did not fully understand the power of his own discoveries and theories of natural selection and evolution. The Beak of the Finch has objectivity and passion. It focuses on rich details, observations made by a curious scientific eye, woven into a great story driven by passion and unfolding discovery. That is why The Beak of the Finch is a Pulitzer Prize winner: because Jonathan Weiner is lucid, impartial, and never questions his motives or his objectivity. It is unflinching, unlike his current book His Brother’s Keeper: A Story From the Edge of Medicine.

Jonathan Weiner said himself that he wanted to write a book that would “take me out of the field and the lab, and into human experience.” That book is His Brother’s Keeper. In some ways, His Brother’s Keeper is a far more complicated book than The Beak of the Finch. Not only does Weiner have to tell the story of the two Heywood brothers, but he presents cutting-edge scientific research for a myriad of neurological diseases, and he profiles the most famous researchers on the planet in genetic engineering, bioethics, cloning, DNA mapping, and gene therapy. Simultaneously, he must cope with his own surfacing revelations about his mother, who has been diagnosed with a rare neurological terminal disease, Lewy body dementia, which might be cured using similar experimental medical procedures that might be used to save Stephen Heywood, who has the preliminary symptoms of ALS. So, His Brother’s Keeper presents more than just the story of Jamie Heywood, who changes his entire life, along with the Heywood family, to save his brother Stephen, who has been diagnosed with ALS. It also reveals the secret innermost struggle of a brilliant author to maintain a journalist’s objectivity, despite the reflections he periodically and freely offers us about his mother, the anecdotes of his childhood years, and his love for her. Weiner would do anything for his mother, just as Jamie would do anything for Stephen, his brother. The two, author and brother, are linked in a desire to change the cards which have been dealt to their loved ones, and a far-reaching, convince-yourself belief that sometimes “anything can happen.” Everything in Weiner’s experience and disciplined scientific journalism tells him that he is getting too close, yet he can’t stop himself. He wants so badly to believe.

The Heywood Family lived in an old house on Mill Street in a suburb of Boston, Newtonville. John and Peggy Heywood had three sons: Jamie was the oldest, then Stephen, and Ben, all exceptionally talented. They were bright, competitive and athletic. John Heywood is a professor of mechanical engineering at MIT. Ironically, the author’s father was also a professor of engineering and applied mathematics at Columbia University, where he attended graduate school. Jamie Heywood grew up in his father’s footsteps, becoming a mechanical engineer. Jamie was not only brilliant, but he was driven, a compulsive personality. His brother Stephen was much more laid back, at ease and “in” with all kinds of people; he hung out with the tough guys, the artists, the actors, the dreamers. Jamie attended MIT; Stephen attended Colgate University, a liberal arts college in upstate New York, where he wrote, painted and approached his studies with a non-scientific manner. After graduating from Colgate, Stephen traveled cross country on his Harley-Davidson in his black leather jacket. With thick black hair, Stephen was tall, athletic and strong, a bulwark, just as Lou Gehrig was described by famous sportswriter...
Jim Murray as “a Gibraltar in cleats.” Both men, Gehrig and Stephen Heywood, were giants of men, who would fall to ALS.

Ironically, it was in 1996 at a dilapidated college in Palo Alto’s suburb of Crescent Park, CA, where Stephen knew that something inside his body was wrong. With his parents’ financial help, Stephen purchased a fixer-upper for $325,000. Stephen became a master designer and builder. For the first time in his life, he found not only something that he really liked, but something which was 100% Stephen Heywood, something that would allow him to use his brilliant mind, his craftsman’s hands, and his eye for elegant original design. But it was months later, after polishing the antique brass door knobs, lock, and decorative escutcheon around the keyhole that Stephen noticed a problem as he tried to unlock the door with the key. With his right hand, the door would not open. Stephen disassembled the lock, adjusted the tumblers, and reassembled the lock. He tried again, but the lock would not open. Frustrated, he used his left hand and click! The door opened effortlessly. Stephen was baffled. That day began Stephen’s journey down the unimaginable road of ALS. As the days wore on, his family and friends would kid him about “his claw” which looked thin and spidery for a man of his stature. Paradoxically, the Crescent House project marked the beginning of Stephen’s life as settled, stable, and professional. He had found himself. On February 28, 1998, about 18 months after he purchased this dilapidated house, it sold the first day on the market for $925,000.

Months later, Stephen went in for a series of neurological tests that confirmed that he indeed had ALS. His brother Jamie was devastated. Jamie suspected that something was wrong in the summer of 1997 when at 30 years old he beat his younger bother Jamie, who was 28, at arm wrestling. It was the first time that had ever happened.

Several months before, Jamie accepted a position as Director of Technological Transfer. Interviewed by Nobel Prize-winning biologist Gerald Edelman, who had founded the Neurosciences Institute in La Jolla, CA, Jamie was hired to be their money man for a technical think-tank group. Jamie was perfect. He knew mechanics, engineering, robotics, and computers, and he was a passionate, relentless salesman. He was the perfect combination of sales hype and technical expertise. For Jamie, it was a job designed in Heaven. However, little did Jamie know that taking this position would begin the greatest turn of his life. It would give him the contacts and the confidence he would need to take on the mission of saving his brother Stephen’s life by soliciting the greatest minds in neurological and genetics research. Outwardly, both brothers were on the fast track of success. They didn’t know what the future held for them.

As the different stories of His Brother’s Keeper unfold, there is one element that snakes its way, most of the time obvious, but sometimes nearly invisible, through the pages of this unusual book. It is stress. It is fueled by time. There is always the proverbial race against time, the race against a death by having your nerves deteriorate and die one-by-one. In his relentless driving, often inconsiderate quest to find a cure for his brother and for a greater ALS cure, Jamie and his wife Melinda’s relationship deteriorates. Stephen and Wendy debate should they get married or not? Have a baby or not? They know the wheelchair world that lays waiting not far down the road for Stephen. The Heywoods struggle to find the necessary finances to keep the cure dream afloat. Famous international researchers struggle with governmental policies, which they see as restrictive in the fight against a plight of neurological diseases, and the author struggles internally with the conflict of his life: remain a pure journalist recording and observing the Heywood story, forgetting about his mother, or identify with the Heywoods and Jamie’s quest to save his brother and use the same strategy to save his own mother.

On a deeper level, His Brother’s Keeper evokes many substantial and conflicting issues that confront us in our momentous time in history. In 1953, Watson and Crick announced to the world that they found the secret of life, the double-helix DNA. In 1959, the first IVF (in vitro fertilization) mammal was born; it was a rabbit. In 1978, the first IVF human being was born. Only seven years ago, the first mammal was cloned, a sheep named Dolly. And, a mere four years ago, scientists announced that they had mapped the complete human genome. Like everything else in our world, scientific advancements and discoveries are happening at light speed.

Author Jonathan Weiner’s strengths are his scientific mind and his ability to translate that information to the layman, so that is not only understandable but sustains the tenor of the scientific curiosity that drives it, and the drama and passion that sculpt it. His Brother’s Keeper presents very real scenarios that are happening behind closed doors today: gene translocation, which could lead to “new species of human beings” who can only reproduce amongst themselves; cytoplasmic transfer, in which an embryo is formed from the DNA of three parents: a donor parent who provides DNA in the mitochondria of the cytoplasm, a mother who provides DNA in her egg, and the father, who provides the DNA in his sperm; stem cell research; and selective genetic engineering at the most sophisticated levels of DNA and gene manipulation.

As Charles Dickens wrote, “It was the best of times, it was the worst of times.” His Brother’s Keeper forces you to think where are we going? How far do we go in our personal and collective quest to improve man’s condition? Should there be limits? And if so, who will set them? Man has always sought to break the envelope. By breaking through the boundaries set by past achievements, you, or in the project group you work with, will win the laurel wreath of fame and reward of money.
We live in the age of corporations. We live in the age of corporate profits and global mergers. At the heart of this great provide, we are losing our identities.

In the author's words, he is an admirer of Lucretius, who said in The Way Things Are that "for then at last words of truth are drawn from the depths of the heart, and the mask is torn off, reality remains."