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The Forever Fix: Gene Therapy And The Boy Who Saved It



Synopsis

Fascinating narrative science that explores the next frontier in medicine and genetics through the very personal prism of the children and families gene therapy has touched. Eight-year-old Corey Haas was nearly blind from a hereditary disorder when his sight was restored through a delicate procedure that made medical history. Like something from a science fiction novel, doctors carefully introduced viruses bearing healing genes into Corey's eyes. A few days later, Corey could see, his sight restored by gene therapy. THE FOREVER FIX is the first book to tell the fascinating story of gene therapy: how it works, the science behind it, how patients (mostly children) have been helped and harmed, and how scientists learned from each trial to get one step closer to its immense promise, the promise of a "forever fix," - a cure that, by fixing problems at their genetic root, does not need further surgery or medication. Told through the voices of the children and families who have been the inspiration, experimental subjects, and successes of genetic science, Ricki Lewis' THE FOREVER FIX is compelling and engaging narrative science that explores the future of medicine as well as the families and scientists who are breaking new ground every day.

Book Information

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Customer Reviews

"In this impressive, meticulously researched study of the exciting new developments in gene therapy, geneticist and journalist Lewis (Human Genetics) looks closely at the history of setbacks plaguing the treatment of rare genetic diseases as well as recent breakthroughs...Yet with each success, as Lewis recounts in this rigorous, energetic work, possibilities in treating HIV infection and

dozens of other diseases might be around the next corner. *Publisher's Weekly* (starred review) "A fascinating account of groundbreaking science and the people who make it possible. Ricki Lewis gives us the inspiring story of gene therapy as told through Corey's eyes--literally. Her book delves into the challenges modern medicine faces--both in its bitter disappointments and great successes--but it goes much deeper than that. With empathy and grace, Lewis shows us the unimaginable strength of parents with sick children and the untiring devotion of the physicians who work to find 'the forever fix' to save them. But best of all Lewis gives us a story of profound hope. Molly Caldwell Crosby, author of *The American Plague: The Untold Story of Yellow Fever, the Epidemic that Shaped Our History* and *Asleep: The Forgotten Epidemic that Remains One of Medicine's Greatest Mysteries* "The Forever Fix is a wonderful story told by one of our most gifted science and medical writers. In the tradition of Siddhartha Mukherjee's *The Emperor of All Maladies*, Ricki Lewis explains complex biological processes in extremely understandable ways, ultimately providing crucial insights into the modeling of disease and illustrating how gene therapy can treat and even potentially cure the most challenging of our health conditions. Dennis A. Steindler, Ph.D., former Executive Director of the McKnight Brain Institute, University of Florida "Ricki Lewis has written a remarkable book that vividly captures the breathtaking highs and devastating lows of gene therapy over the past decade while giving ample voice to all sides -- the brave patient volunteers, their parents and physicians. The Forever Fix is required reading as we dare to dream of curing a host of genetic diseases. Kevin Davies, Founding editor of *Nature Genetics*; author of *The \$1,000 Genome* and *Cracking the Genome* "In 'The Forever Fix,' Ms. Lewis chronicles gene therapy's climb toward the Peak of Inflated Expectations over the course of the 1990s. A geneticist and the author of a widely used textbook, she demonstrates a mastery of the history. The Wall Street Journal "An engaging and accessible look at gene therapy. Times Union "Medical writer Ricki Lewis interweaves science, the history of medical trial and error, and human stories | from the death in 1999 of teenager Jesse Gelsinger, from a reaction to gene therapy intended to combat his liver disease, to radical successes in some children with adenosine deaminase deficiency. Nature "Lewis adeptly traverses the highs and lows of gene therapy and explores its past, present, and future through the tales of those who've tested its validity. The Scientist

RICKI LEWIS is a Ph.D. geneticist, journalist, professor and genetic counselor. The author of one of

the most widely used college textbooks in the field (Human Genetics: Concepts and Applications, now in its 10th edition), she has also written hundreds of popular pieces on science and other topics for trade and specialized magazines, including Nature, Discover, and The Scientist.

I started out as just another pre-medical freshman at Duke University in 1988, but I soon discovered that there was a prevailing mentality ruling mainstream science that was anathema to me, so I failed to thrive and maintain interest in the health sciences, bouncing around from one field to another within the sciences over the years. Most recently, after an aborted educational start in the field of natural medicine, I've come to the conclusion that -- aside from a much-needed nutritional revolution, the other half of what simply must happen in order to advance a TRUE health improvement revolution -- we simply must attack those intractable problems of human health for which dietary and nutritional changes simply would either not be reasonably sustainable, or at all sufficient. Much to the enraged chagrin of the Rockefellerian petro-pharmaceutical mafia that has ruled human health since the very late 1800's, we must find a way to actually repair maladaptive genes themselves and finally break the shackles of undue drug dependency once and for all. With all that said, I was delighted to find Ricki Lewis' book. She, perhaps alone, truly gets it. She truly understands that the nature of the problem is, as she so rightly puts it, "science for science's sake", rather than for the sake of the greater human race who sincerely needs what would otherwise be its civilizing fruits. Dr. Lewis has written a book that, to my knowledge, is singular of kind: it really gives a damn about the good, and shows us clearly and plainly how we may not only get there, but how we have already begun to get there -- to lasting and humane fixes rather than deliberately temporary and purely profiteering temporary band-aids.

The Forever Fix is a great read. Ricki Lewis delivers the history of gene therapy and tells the incredible story of Corey Haas in a way that is smart and engaging. The author makes the technical process easy to understand, even for those of us who are not scientists. The Forever Fix delves into other stories of gene therapy--including the epic failure that was the Jesse Gelsinger case--and provides a comprehensive view of how far the technology has come in the past few decades. This would have been an ideal book to read in some of my undergrad biotech/ human genetics courses. Given the multiple distractions of the Text Messaging/ Facebook era that we live in today, Ricki's approach of jumping from story to explanation, from anecdote to story, is refreshing and keeps readers engaged. I currently work in the biopharma industry and would also recommend this book to professionals looking to ramp up on gene therapy, as this is surely not the last we will hear of the

groundbreaking technology.

I have been trained as a scientist and found this book to be fascinating. I remember taking a course in bioethics and learning of its renewed importance in the age of gene therapy. Unfortunately, the author chooses to concentrate on one case which she identifies as being true gene therapy when in fact, it is a partial treatment and may only be successful in a very small subset of young patients. The explanations of the genetics involved and the biological mechanisms used are primarily a means of showing off the author's talents. Having written a textbook for undergraduate students, I am sure she is knowledgeable but this should not be read as a textbook, but as a biographical description of what can go wrong and what can go right when gene therapy is attempted. Nevertheless, it does hold the reader's attention and that is no small thing when explicating such a difficult subject.

As a disclaimer I should say that genetics is part of what I do at work, even though I don't work on gene therapy in particular. But aside from the topic, which I knew I would enjoy, I loved Dr. Lewis's writing and the way she effortlessly folded all the science (and the history of science) into the narrative. I am grateful to Dr. Lewis because through this wonderful book she humanized scientific research, giving a voice to the struggle of many patients and their families. She gave a voice and face to the doctors and the researchers who face many failures for every small step forward. Science is not dry and impersonal. Science is made of people, not just the scientists, but also the people who ultimately benefit from it, and the ones who, due to unfortunate events, didn't benefit but were still part of what made the successes possible. A wonderful read and a truly touching story.

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