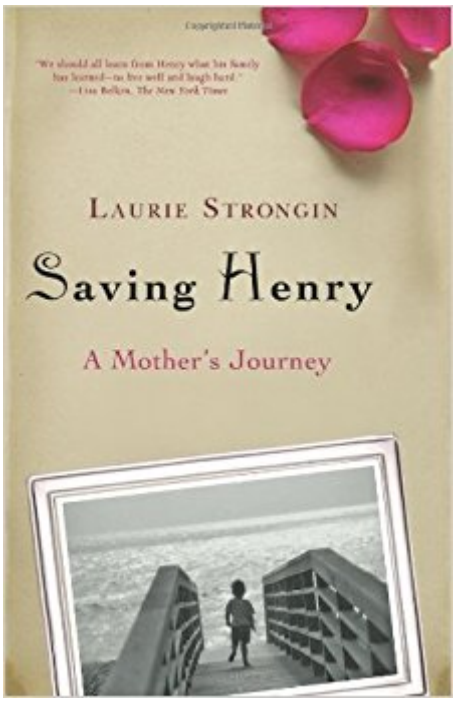
Saving Henry: A Mother's Journey



Synopsis

"A heartbreaking story, exquisitely told . . . Laurie Strongin’s integrity, humanity, and wisdom are an inspiration to the rest of us."--David Shenk, author of The Forgetting Saving Henry is the eye-opening and inspiring story of how far a family will go to save the life of their child. Laurie Strongin’s son Henry was born with a heart condition that was operable, but which proved to be a precursor for a rare, almost-always fatal illness: Fanconi anemia. Deciding to pursue every avenue that might provide a cure, Laurie and her husband signed on for a brand new procedure that combined in vitro fertilization with genetic testing to produce a baby without the disease, who could be a stem cell donor for Henry. As Laurie puts it: "I believe in love and science, nothing more and nothing less." Laurie and her husband endured nine failed courses of the procedure before giving up. But Saving Henry is also about hope. It is the story of Henry, the feisty little boy who loved Batman, Cal Ripken Jr., and root beer-flavored anesthesia, and who captivated everyone with his spunk and positive attitude. When the nurses came to take blood samples, Henry brandished his toy sword and said, "Bring it on!" When he lost his hair after a chemo treatment, he declared, "Hey, I look like Michael Jordan!" Laurie became a fervent advocate for stem cell research, working with policymakers and the scientific community to bring attention to Henry’s case and to the groundbreaking research that could save many lives. Henry’s courage and bravery inspired nurses, doctors, friends, and family. Saving Henry is the story of one family’s search for a cure, and the long-lasting scientific impact their amazing little boy has had. Praise for Saving Henry "How do you make beauty and meaning out of unimaginable sorrow? Saving Henry is a stirring account of struggle, love, and loss that manages to be both honest and inspiring."--Rabbi David Wolpe, author of Making Loss Matter and Why Faith Matters "Henry’s story is important and newsworthy; a testament to how the debate over medical technology and stem cell research is not just an academic argument, but also a searingly personal one. Mostly, though, it’s an intimate love story. We should all learn from Henry what his family has learned--to live well and laugh hard."--Lisa Belkin, journalist, The New York Times "Saving Henry is a marvelously told tale of love triumphant. Parents often say they would do anything for their children. This is the story of a couple that actually did."--Jeffrey Goldberg, national correspondent, The Atlantic "There’s a reason Saving Henry rings with so much truth: the author lived every word of it. It’s a vivid, beautifully rendered, and almost painfully honest account of a journey none of them wanted to take, but could not avoid, thanks to a bad throw of the genetic dice. Laurie, her husband Allen, and especially little Henry, become pioneers in a landscape of complex technological procedures that offer hope but also bring pain . . . and yet they keep trying. This is a tale of a family that will not quit."--John Donvan, correspondent,

ABC News "Strongin has a gift for telling a complex medical story as an unfolding family narrative--a family that in so many ways is my family, your family, anybody's family. Any of us in today's world could find ourselves facing the difficult and challenging set of decisions this family had to make. Strongin's story is a truthful and honest road map we may want to follow."--Dr. Ranit Mishori, contributing health editor, Parade Magazine; professor, Georgetown University School of Medicine

Book Information

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Customer Reviews

The subtitle shorthands Stronginâ ™s ongoing battle with her baby Henryâ ™s rare and fatal disease, Fanconi anemia. In 1996, when Henry was six months old, she learned she was pregnant and also her preimplantation genetic diagnosis (PGD), the result of a procedure â œcombining in vitro fertilization with genetic testing conducted prior to embryo transfer.â • PGD could identify and implant an artificially conceived embryo whose umbilical cord blood, collected at birth, and stem cells, transplanted to Henry, could cure Henryâ ™s disease. Laurie and husband Allen were the pioneer PGD couple, unsupported by precedents, support groups, ethical guidelines, or regulations of any sort. Shortly after Jack was born healthy, Mark Hughes, an essential medical-team member, was charged with violating the newly established federal ban on stem cell research, and his previous work was lost. Months passed. Henryâ ™s blood counts fell. Finally, Hughes found work â œabsent the governmentâ ™s stranglehold.â • Strongin smoothly integrates medical information into this compelling tale of fear, helplessness, frustration, and unflagging love for a beautiful

childâ ™s spirit. Sure to inspire many readers. --Whitney Scott

"Saving Henry is a marvelously-told tale of love triumphant. Parents often say they would do anything for their children. This is the story of a couple that actually did. Laurie Strongin, a woman of true gifts, will break your heart, and fill you with joy. This is an astonishingly good book by a mother who understands that in the battle between love and death, it is love that always wins."â ”Jeffrey Goldberg, National Correspondent, The Atlantic"Any mother and any father will immediately understand why Laurie Strongin did what she did. As a doctor I know that all the science being developed, all the technology being perfected, all the studies in the medical journals, in the end, are about people and families, like Strongin's family.Strongin has a gift for telling a complex medical story as an unfolding family narrative a family that in so many ways is my family, your family, anybody's family. Any of us in today's world could find ourselves facing the difficult and challenging set of decisions this family had to make. Strongin's story is a truthful and honest roadmap we may want to follow."â ”Dr. Ranit Mishori, Contributing Health Editor, Parade Magazine; Professor, Georgetown University School of Medicine

This book is about the life altering devastation a genetic disease can cause in a family, and especially in the parents. Ms. Strongin tells a tale of two parents desperately balancing enjoying the limited number of days Henry has with the unwavering optimism that science and a little luck can save him. This book is described as honest because Laurie tells you in her own voice the good days, the bad days, and the little thoughts that she could never say out loud during her oldest son's life. It is heartbreaking because Henry's disease is such a small part of who he is, but it is that small part that consumes him. It tells the story of a happy young boy, an adoring little brother, and two parents who are giving every ounce of energy to their boys and leaving nothing for themselves. It is impressive that Laurie focuses such equal attention on both sons, given the circumstances. I am glad I read this book.

This is an amazing story about a family's determination to make their child's life rich, fun and full despite his terminal illness and the stress it put on their family. It is also the story of a little boy who was a wonderful, kind and fun-loving person, not just an illness. His life and the efforts of his parents to save him led to significant research that continues to help others with rare disorders to this day.Henry's parents went to all the lengths they possibly could to try to use selective embryonic transfer / IVF in its early stages in an attempt to ensure the health of their next child, as well as the

possibility that their next child could be a lifesaving stem cell donor who could save Henry’s life. It was their little boy’s only hope of a cure. Unfortunately, when then-President George Bush put a stop to most government-funded stem cell research, their efforts were significantly delayed, causing a slowdown that was one of the contributors to this precious little guy’s demise.Don’t let the sad factors of this story deter you from buying the book. Henry and his family are an inspiration and their story is well worth reading and sharing.

This was a beautiful story of a family’s journey to save their son’s life. I found myself reading this until my eyes were tired and then looking forward to the next day to see what Henry was up to. This book is a beautifully written account of their son’s (and theirs) spirit through a very difficult time in their lives, I commend Henry’s parents for making every effort to search for a cure for their son while also enjoying every moment of life with not only Henry but their other children. Well done.

Remember the girl you knew in high school who was in the homecoming court and captain of the field hockey team? The one who was cute as a button and didn’t have a care in the world? The one you knew would always have a life of ease? Well, not so fast.In 1995, Laurie Strongin gave birth to her first son, Henry Strongin Goldberg, who was born with Fanconi Anemia, a rare genetic disorder which is almost always fatal. His birth coincided with the development of PGD (Preimplanation Genetic Diagnosis) for use in conjunction with harvesting perfectly matched, umbilical cord stem cells, an untested medical procedure that would allow Laurie and her husband Allen to give birth to a perfect donor sibling for a life saving bone marrow transplant for Henry - if only they had enough time!Laurie’s account is a race through the fascinating science and politics in which Henry and his parents found themselves front and center. And although they faced profound political and medical setbacks, the family kept an unabiding fighting spirit and sense of joy which defines true heroism. At the center of course is Henry, an energetic, funny kid who never doubted that he was getting better and charmed everyone he met (including Bill Clinton and Cal Ripkin) along the way.This is also the very candid personal story of Laurie, who grew up privileged and popular and always "made the team, secured the invitation, got the guy." To make the transition from someone whose biggest concern was what new fun adventure she would have that day to administering eighteen different, perfectly-calibrated kinds of medications around the clock through an IV connected into her child’s chest, while scrubbing and disinfecting every surface her son might happen to touch, with an even younger son at home, while pregnant with the third son, while fighting a political battle on the front page of the "New York Times Magazine" and on "Nightline" about one of the most complex medical

and ethical issues of our day is quite a gripping read. By the end of this book, you are filled with admiration for Laurie, her husband Allen, the team of doctors at the forefront of PGD who treated Henry and of course Henry himself, whose ordeal has already benefitted so many others.

Henry's parents determination to keep a positive attitude is the strongest I have ever seen

This book was great! My family recently went through the same situation with my niece but it was, in some ways, really amazing to read about it from different eyes. Laurie did a wonderful job of explaining the science of this disease so that people not close to the disease can really understand it better....I am excited and honored to meet her at an upcoming book party! I will be recommending this book to a lot of friends who know some of what my family went through and many people that don't! Thank you for sharing with us Laurie!

An amazingly poignant story, well written and very personal. Brilliant to see such a moving story also be able to capture the realities of politics and science in a way that the reader can really understand. What a journy for this family and amazing contribution to other children that Henry made.

This true story, will be the best read you have ever had about a family struggling to survive. I was captivated by it, and did not put it down until it was done.Bravo to Laurie Strongin on the best writing ever done about Fanconi anemia.

Bonuses Included) (Finance, Personal Finance, Budget, Budgeting, Budgeting Money, Save Money, Saving Money, Money) Soluble Fiber: Saving Your Health, Saving Your Money DIY Energy & Money Saving Solutions â “ Best Practices Volume 1 Landscape Hedge (Simple DIY Money Saving Green Solutions) Going Blue: A Teen Guide to Saving Our Oceans and Waterways: A Teen Guide to Saving Our Oceans, Lake Saving Charlotte: A Mother and the Power of Intuition Saving Each Other: A Mother-Daughter Love Story Saving Sammy: A Mother’s Fight to Cure Her Son’s OCD My Mother, Your Mother: Embracing "Slow Medicine," the Compassionate Approach to Caring for Your Aging Loved Ones The Mother’s Songs: Images of God the Mother Mother of the Unseen World: The Mystery of Mother Meera The Mother-to-Mother Postpartum Depression Support Book: Real Stories from Women Who Lived Through It and Recovered