Bio

GINA KOLATA (M.A.) is a writer and medical reporter for The New York Times. She has previously written five books and edited three collections of popular science writing. Ms. Kolata lives with her husband in Princeton, New Jersey.

Summary

A work of narrative nonfiction in the tradition of the The Immortal Life of Henrietta Lacks; Mercies in Disguise is the story of a family that took matters into its own hands when the medical world abandoned them. It’s a story of a family that had to deal with unspeakable tragedy and yet did not allow it to tear them apart. It is the story of a young woman—Amanda Baxley—who faced the future head on, determined to find a way to disrupt her family’s destiny.

The phone rings. The doctor from California is on the line. “Are you ready Amanda?” The two people Amanda Baxley loves the most had begged her not to be tested—at least, not now. But she had to find out.

If your family carried a mutated gene that foretold a brutal illness and you were offered the chance to find out if you’d inherited it, would you do it? Would you walk toward the problem, bravely accepting whatever answer came your way? Or would you avoid the potential bad news as long as possible?

In Mercies in Disguise, acclaimed New York Times science reporter and bestselling author Gina Kolata tells the story of the Baxleys, an almost archetypal family in a small town in South Carolina. A proud and determined clan, many of them doctors, they are struck one by one with an inscrutable illness. They finally discover the cause of the disease after a remarkable sequence of events that many saw as providential. Meanwhile, science, progressing for a half a century along a parallel track, had handed the Baxleys a resolution—not a cure, but a blood test that would reveal who had the gene for the disease and who did not. And science would offer another dilemma—fertility specialists had created a way to spare the children through an expensive and morally taxing process.
Early Reader Praise for
Mercies in Disguise

“I found this ‘medical mystery’ very informative and extremely interesting and had a hard time putting it down! The family that was followed became my friends and I was quite emotionally involved in their story. The author does a good job balancing the technical information with the true circumstances of the Baxley family. If you liked The Immortal Life of Henrietta Lacks you will enjoy this book! Great for book clubs.” — Sandra (Delray Beach, FL)

“Unlike the fictionalized O’Briens (Inside the O’Briens by Lisa Genova), the Baxley family members are real and will touch your heart. ...This book will stimulate your thinking and will make you grieve for the family members who must face uncertainty (and certainty) in their futures. You won’t be the same once you’ve come to know the Baxleys.” — Maribeth (Indianapolis, IN)

“I read it in one sitting since it hit home for me on many levels, recently losing a loved one to a neurological disease and having a close family member go through the same embryo screening procedures at the same lab because of a different genetic condition. I find medical research extremely interesting and the author presented it in a way that kept my interest.” — Lisa G. (Wheeling, IL)

“I wasn’t sure what to expect when I received this book, but I couldn’t put it down. It was so intriguing and so fascinating, I found it hard to believe that it was true. This is thought provoking, not only about the ethical questions raised regarding genetic testing for this rare disease, but for issues in IVF, and even BRCA testing. And my heart breaks when I think about Amanda’s future.” — Peggy (North East, PA)

“I devoured this book in less than a day. The author, Gina Kolata, does a masterful job introducing the reader to a little known genetically inherited disease with no cure. The story introduces us to a small town Southern family giving GSS a ‘real’ face. You will love and admire these people as you follow their story and their quest to diagnose the illness that has manifested itself in the family’s patriarch. ...I cannot say enough about the dignity and courage of this family as they make their decisions once they learn the identity of this disease and it’s physical impact on their loved ones. I was left wondering, what would I do? It’s a beautiful story and hopeful despite this disease’s inevitable physical impact.” — Barbara (Maryland Heights, MO)

“Well-written, informative, well-developed characters. I found myself sad to see the book end. I will look for more books by Kolata.” — Carol T. (Ankeny, IA)

“This was a fascinating explanation of a little known disease that is described as being somewhere between Parkinson’s and Alzheimer’s. The decisions to be genetically tested seemed agonizing and the consequences of living with the outcome of the testing even more so. Adding the Baxleys’ stories to the book made it so much more personal and human. ...I found this book to be one of most easily understood medical/scientific portrayals I’ve ever read. It sounds cliche but it read like a mystery/thriller.” — Anne (Austin, TX)
Book Club
Discussion Questions

• What is the meaning of the title, Mercies in Disguise? What mercies are apparent for the family members? Do the family members see different mercies?

• If you knew that you were at risk for a fatal genetic condition that had no cure, would you want to be tested for the genetic mutation? Why or why not? What if the person at risk were your child? Your spouse?

• Why do you think the history of the Fore in New Guinea was included? How did the discovery of Kuru lay a foundation for discoveries about GSS and other prion diseases?

• What role do chance or coincidence play in scientific discoveries discussed in the book? What role does scientific collaboration play?

• What role did each member of the family (Tim, Mike, Buddy, and the others) play in uncovering the diagnosis? Would they have been likely to find a diagnosis without this collaboration?

• Why was it so difficult to obtain a diagnosis, even in a family with medical backgrounds and with access to expert neurologists?

• How does knowing that they have the mutation affect some of the individuals in the book? Are there unexpected consequences from knowing their diagnosis? How are individuals who learn they do not have the mutation affected by that knowledge?

• How do you feel about the choice of a family member who opts not to be tested? Can you understand their POV?

• Each individual makes their own decision to pursue genetic testing. How much do religious views versus scientific knowledge impact their decision? Are religious views necessarily at odds with scientific mindviews?

• How does our increasing ability to test for genetic illnesses before they occur affect your views on the importance of protecting the privacy of medical records?

• How did Bill Baxley, Sr.’s experience with the disease differ from that of his sons? Did knowing the name of the disease affect Billy and Buddy’s hope as the illness progressed?

• Why did Amanda’s mother, Kathy, ask her to wait to be tested until after her father had died? Do you believe her father, Buddy, wanted her to be tested? Why or why not?

• Which Baxley family member did you find yourself relating to the most? Why?
Support Group
Discussion Questions for Patients and Families

• Each person who is tested is confronted with the question (page 1): “Which life will it be? The one in which the years stretch outward boundlessly or the one where the future twists into a discernible, ghastly shape?” After coming to this crossroads, how would your life be different if you discovered that you did not have the gene? Do you think you might feel guilt?

• What are the consequences of being aware that you will likely develop a medical condition that will end your life at an early age? How would/are you using this knowledge to shape your everyday decisions?

• Among Amanda’s siblings, one has the genetic mutation, one does not, and one was not tested. How might these facts affect their relationships? How does one sibling’s decision impact the others?

• What roles do religious affiliation and religious beliefs play in the decisions made by the various family members? What role does it play in how you feel about medicine’s ability to reveal our future?

• Amanda tells her children that she wants to take them to Victoria Falls. Why is this place significant to her? To what extent are her young children likely to understand what is ahead for their mother? If you were in Amanda’s situation, what would you tell your children and when?

• Once you became aware that a condition such as GSS or CJD existed in your family, did you encourage your children to learn their medical status? Why or why not?

• How did Amanda’s mother feel about PGD? In what ways did she support Amanda? Would you be able to put aside your religious or ethical objections to support your child? Has your family had a similar experience?

• Why do you believe it takes so long for treatments to emerge for a disease like GSS, even after the genetic mutation has been discovered?

• Why do you think the family chose to share their story so openly? What impact could that have for them in both positive and negative ways? How has sharing this story affected you? Are you more or less likely to share your own?

Links for other support resources:

Alzheimer’s Association: www.alz.org
Centers for Disease Control and Prevention (CDC): www.cdc.gov
Creutzfeldt-Jakob Disease (CJD) Foundation Inc.: www.cjdfoundation.org
CJD Aware!: www.cjdaware.com
National Organization for Rare Disorders (NORD): www.rarediseases.org