

## ***Mercies in Disguise***

by Gina Kolata

Kolata, a science journalist for the *New York Times*, shares the gripping story of how one South Carolina family has dealt with a deadly and untreatable genetic illness. The book considers a number of ethical issues as well as the way faith and medical science intersect for the family.

1. Memory plays a significant role in the retelling of the Baxley family. We are first introduced to the idea that there might be connections between the death of her grandfather and his father via an offhand comment at a funeral. How else does Kolata use memories, rather actually recalled or imagined, to further the story along?
2. Amanda Baxley is the central figure in the latter half of the book, yet Kolata spends relatively little time on her in the first half, choosing instead to draw out the history of prion disease research. In what ways did the science in the first part of the book impact your feelings toward the second half? Was the scientific history useful or a distraction? Why or why not?
3. In the introduction, the author asks the question, “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?” Were there points in the book that altered your initial answer to that question, and why?
4. Kolata begins by defining an obscure Africa disease called kuru as “to be afraid.” The mystery of this disease becomes the impetus for research that eventually leads to the naming and discovery of GSS. As she is awaiting the news of her test results, Amanda goes on a medical mission trip to Zambia. In what ways are these vignettes of Africa related, or are they happenstance in the story?
5. How do the various family dynamics play out as the story unfolds? How could you imagine your own family reacting to this kind of news and what roles would various people assume?
6. Hope, Luke, and Amanda Baxley all come to different conclusions regarding being tested for the GSS mutation. Hope, in particular, states that finding out if you have the mutation demonstrates a lack of faith in God. Do you agree with this? Can a person be faithful to God and still want to know this type of answer?
7. Amanda and Brad face the ethical question about genetically screening embryos for the GSS mutation prior to IVF. This is ultimately tied up with many questions regarding abortion, ‘designer babies,’ and the role science has in circumventing nature. Ultimately six embryos are found to have the GSS mutation and discarded, followed by a period of mourning for Amanda. How did you react to this scene? Were you sympathetic or unsympathetic? What questions did this raise for you?
8. Although Amanda finds reprieve in Africa, at the end of the story she is not as happy as she used to be. Kolata writes that, “Knowing is exhausting.” The adage, “ignorance is bliss,” springs to mind as a juxtaposition to Kolata’s declaration. At the same time, if Amanda’s test had been negative, would that knowledge still be exhausting? Is there a point when knowledge is blissful and

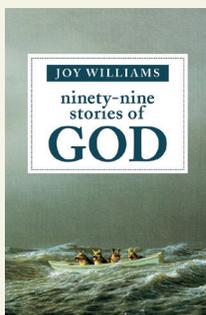
ignorance is exhausting? How did you react to the conclusion of the story?

9. Throughout the story, there is an underlying tension about the relationship between faith and science, especially in regards to genetics and reproduction. Pop culture often posits that one must choose either faith OR science. Yet, Francis Collins, director of the National Institutes for Health and former leader of the Human Genome Project, is a devout Christian and has said, “I believe God did intend, in giving us intelligence, to give us the opportunity to investigate and appreciate the wonders of His creation. He is not threatened by our scientific adventures.” How do you respond to Collins after reading this book? How would you have responded before? If that has changed, what provoked it?

10. Mercy is often described as not receiving what is due to us because of our behaviour, as in, God is merciful in not punishing us for our sinfulness because of Christ. Kolata includes a quote from Laura Story and her song “Blessing” in the start of the book, and seems to draw the title Mercies in Disguise from this song. Where is mercy located in this work? Is it in the mercy of Amanda and Brad to not pass on the GSS gene to their children? Is it in the mercy shown Amanda by her mother Kathy? Is this an apt name of the work?

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# NEXT MONTH



## *Ninety-Nine Stories of God*

by Joy Williams

In Williams’s hands, a “story of God” can apparently be almost anything. This thin collection of 99 stories is funny, unsettling, and mysterious, to be puzzled over and enjoyed across multiple readings