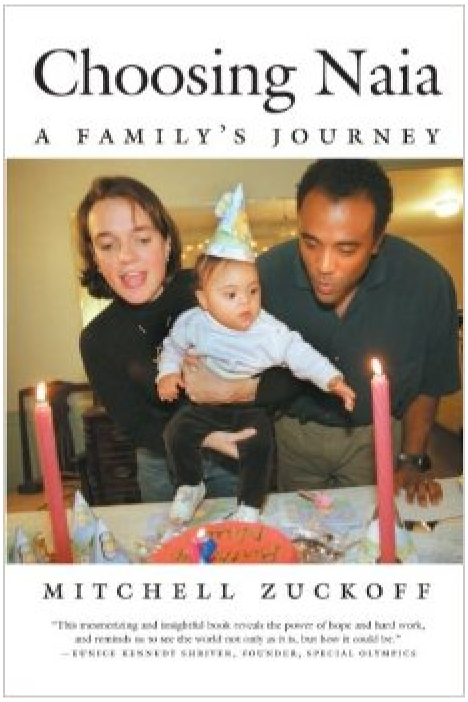
Choosing Naia: A Family's Journey



Synopsis

A dramatic and carefully detailed account of one family's journey through the maze of genetic counseling, medical technology, and disability rights; destined to become required reading for anyone touched by any of these issues.

Book Information

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Customer Reviews

Greg and Tierney Fairchild are a well-educated, middle class couple who are thrilled to discover that Tierney is pregnant. Tierney undergoes all of the usual tests, and the Fairchilds are stunned to discover that their unborn child has a hole in her heart and may also be afflicted with Down syndrome. Investigative reporter Mitchell Zuckoff spent hundreds of hours with Tierney and Greg, and the result is "Choosing Naia," a book that began as a series of articles in the Boston Globe. This is the story of a couple's arduous journey, an eye-opening look at the history of Down syndrome, and a detailed explanation of what such a diagnosis means for the child and his parents.Zuckoff's conversational style makes "Choosing Naia" flow smoothly. The author explores such topics as genetic testing and counseling, the value of networking, and the importance of early intervention for children with Down syndrome. "Choosing Naia" stands out for its unflinching honesty. It is a tribute to the Fairchilds that they allowed their doubts, fears, and uncertainties to be recorded for posterity. They come across as vulnerable people whom we grow to admire for their determination to face a difficult challenge with strength and courage..

I just finished reading "Choosing Naia" and very much enjoyed it. I have a six year old boy with DS who was diagnosed when I was 20-21 weeks pregnant. I was interesting to see some of the similarites between my families situation and reactions and the Fairchilds. I would highly reccommend this book. I do not feel there was undue emphanise on the potenital abililies or inabilities of the unborn child. I have a hard time believing anyone in this situation would not have those thoughts. I feel everyone wants a child who is happy ,interactive and to some degree self suffient. The issue of abortion was explored and I found it interesting to profile a couple who had made the decision to terminate. It is amazing the technology availble to diagnose DS during pregnancy but I personally wished I had not known before the birth of my son. Knowing ahead of time ruined the joy of my first pregnancy He was born without any health problems which was a blessing. Mattie is not what I would consider high functioning (not talking or potty trained) but he is his own person and can't imagine life without him. Having a child with DS is not the end of the world or even close.

Some of you in the Boston area may have seen the series that ran in the Globe last year, the author expanded it into a book. It profiles a couple who gets back the AFP results showing an increased risk for abnormalities, has the amnio and then has to choose between having a child with Down syndrome or terminating the pregnancy and trying again. The author, Mitchell Zuckoff, spoke at the National Down Syndrome Congress convention in Denver back in August and said that his original intention with the series was to show how advances in technology present us with very serious choices and explore how different families deal with them. The book is not at all preachy in either the pro-life or pro-choice direction, very balanced. It really makes you think about the nature of the challenges of parenthood and how our choices play out.

What do you do when your worst fears come true? That's the question that faces this remarkable couple, Greg and Tierney Fairchild, when they're expecting their first child. The way they answer that question is an incredible story -- suspenseful, riveting, enlightening -- and it affects all of our lives. Although they have to deal with a diagnosis of Down syndrome and a heart defect, the point of this remarkable book is that our ability to know what's going on in the womb is outpacing our capacity to deal with that knowledge. Seeing how the Fairchild family deals with it, and watching them grow along with their daughter Naia, makes for a fabulous read.

This book made me sick. Literally. An entire book where the dramatic tension is whether or not a mother should murder her child. Why would I ever want to recommend that to anyone? What incredible blindness to still maintain that parents should have the right to make this decision, should have the right to Ã¢Â Âœchoose EITHER life or deathÃ¢Â Â• for their precious child, as they stare at the beloved face of their own child. How can they tell their other children with a clean conscience Ã¢Â Âœmommy & daddy are so glad they didnÃ¢Â Â™t kill NaiaÃ¢Â Â”but you know, we really hope some parents get to have the chance to kill other kids like her.Ã¢Â Â•? Revolting. ESPECIALLY when they explored the adoption option and saw the reality that hundreds of families want to adopt a child with DownÃ¢Â Â™s syndrome, and are willing to wait years and years for that privilege. How dare they kill a child whom someone else is more than happy to deem Ã¢Â Âœperfect,Ã¢Â Â• even if they are so blind they cannot do so?? God will harshly judge genetic counselors who do not do everything in their power to turn aside parents from the folly of filicide.The one helpful thing I took away from this book was the point made that early diagnosis of disabilities may not actually be a good thing. Not only does it not improve outcome in many cases (a delay of merely several hours in needed surgery, for instance), but it forces a parent to view their childÃ¢Â Â™s disability out of context. All they know about this baby is that it has ___ wrong with it. They havenÃ¢Â Â™t seen its precious face, havenÃ¢Â Â™t felt her grip their hands, havenÃ¢Â Â™t heard their tiny voice. If they had, they would not dare deny that this child is more than the sum of its physical parts, working or non. While I personally do still see benefit to one diagnostic ultrasound, as lacroscopic surgery has enabled the treatment of disabilities during fetal development instead of after delivery, when it is too late, such as in the case of spina bifida or certain tumors. I would encourage expectant parents (I do NOT use the term Ã¢Â Âœparents to be,Ã¢Â Â• because they already are parents, responsible for the constant care of this precious human soul) to seek an ultrasound if they so desire, knowing that they will only use the knowledge to seek to better care for their child instead of potentially cast him or her aside.

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