

Moonrise



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Moonrise is Penny Wolfson's first-person account of her family, her son Ansel, and his progressive disability, caused by the genetic disease Duchenne muscular dystrophy. The journey begins when he is born and deemed a particularly beautiful and magical baby, continues with the alarming possibility, at the age of two, of "wrongness," takes us through the diagnosis of disease and prognosis of early death, and brings us to his adolescence, where his parents are never sure if the moon is rising or setting over his life. As she traces her son's development and the impact of his disability on her worldview, she embarks on a quest to understand scientific advances and their implications. (The gene was isolated at approximately the time Ansel was diagnosed.) She also explores special education, giftedness, prenatal testing, and the genetic links she shares with her mother, sisters, and son. Questions about the disease-causing mutation persist: What does knowledge of the self on a molecular level mean? Is genetic self-knowledge our goal now, much as knowledge of the psyche was in the last century? Moonrise is an essential contribution to the dialogue about genetics, as well as a deeply human story about a remarkable child and his family.

作者介绍:

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