



The Light of One Star

Anne Fischer Juhlmann

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Memoir The Light of One Star is a record of the online journal that Anne kept from 2003--a year before her first child--seven-year-old Sam--died of mitochondrial disease until December 2007, just a few weeks after her second child--fifteen year old Zachary--died of this same disease. It is above all else, the chronicle of a mother's fierce love for her children, but it is also a medical story--records of lab results, worries about specific drug effects, decisions about surgeries that the boys underwent. More importantly, it is about what happens when doctors include parents in the decision making, about the importance of a doctor admitting "I don't know," about residents who take time to play Yugio with a child, about a hospital security guard who files a missing person report for a stuffed animal. Mostly, despite the devastation wrecked by mitochondrial disease on her children, her family, on her--Anne's story, like her boys' lives--is filled with refulgent moments, shimmering with gratitude and humor and yes, even joy.

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