



Orphan: The Quest to Save Children with Rare Genetic Disorders

Philip R. Reilly

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Orphan is about the struggle to save the lives of children who, because of an unlucky roll of the genetic dice, are born with any one of several thousand rare genetic disorders. Many are burdened with diseases that carry mysterious names, some of which you can read about for the first time in this book, along with compelling stories about the physicians, scientists, and parents who have taken them on. The diseases include phenylketonuria, sickle cell anemia, dystrophic epidermolysis bullosa, X-linked hypohidrotic ectodermal dysplasia, and Friedreich's ataxia—just a few of the more than 1000 genetic disorders that are well-described and many more that are not. Many manifest in infancy. Some show up in mid-childhood, others later in childhood, and still others among adults. They touch almost every extended family. *Orphan* is more than a book about disease and research—it gives voice to thousands of people who, all too often, have endured terrible illnesses, bravely faced arduous clinical trials, and, sometimes, have gained victories, almost always in silence. This book recounts extraordinary breakthroughs and hopes for the future. Many of the disorders that will end our lives are in some part genetically influenced. We really are all orphans, and this book is for all of us.

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