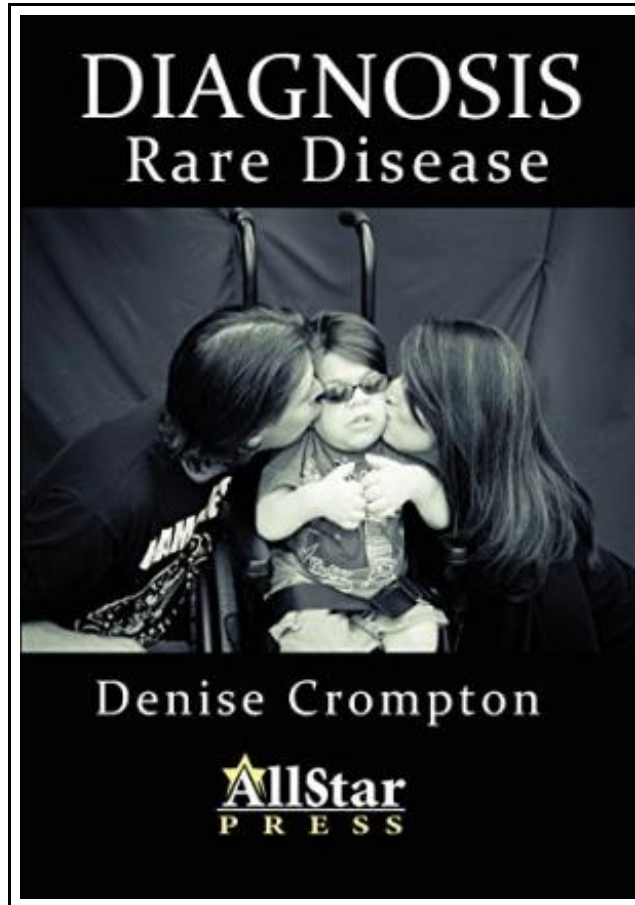


Diagnosis: Rare Disease



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Reviews

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All Star Press, United States, 2014. Paperback. Book Condition: New. 241 x 168 mm. Language: English . Brand New Book ***** Print on Demand *****. Rare Disease the diagnosis that no parent ever wants to hear. This book gives a heartbreaking expose of what life is like for families that have a member with a rare disease, explains Carolyn Paisley-Dew, ISMRD Board Member. It follows the journey of 13 families who have one or more children with a rare disease called Mucopolysaccharidosis, as they waded through the erratic diagnosis process, medical muck-ups, endless pain, a plethora of medical appliances and home modifications, special education, multiple hospitalizations and surgeries, unrelenting stress and the ever-present fear of death. The book highlights how stoic, resilient, strong and resourceful these families are, and how heartless, or thoughtless, some medical professionals can be. It underlines the importance of networks to allow these isolated families to support each other and to give them a sense of belonging. Author Denise Crompton presents these stories in a style that is compassionate and easy to read. Other families with a rare disease will recognize themselves in this book. It is a must for medical professionals, especially those who want to understand the families and how to best work with them during these difficult times. What Others Are Saying About this Book: Wow, breadth depth: The various chapters of Diagnosis: Rare Disease cover every aspect of the impact of a rare disease on individuals. Within each chapter is deep insight into the tremendous differences of impact on each of 15 Individuals. In addition the style is compelling reading. Bob Gorman - Independent Research Professional Denise Crompton captures the essence of living with a rare disease; the quest for a diagnosis, the fears, frustrations, heartbreaks, navigating the medical establishment, and the...

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