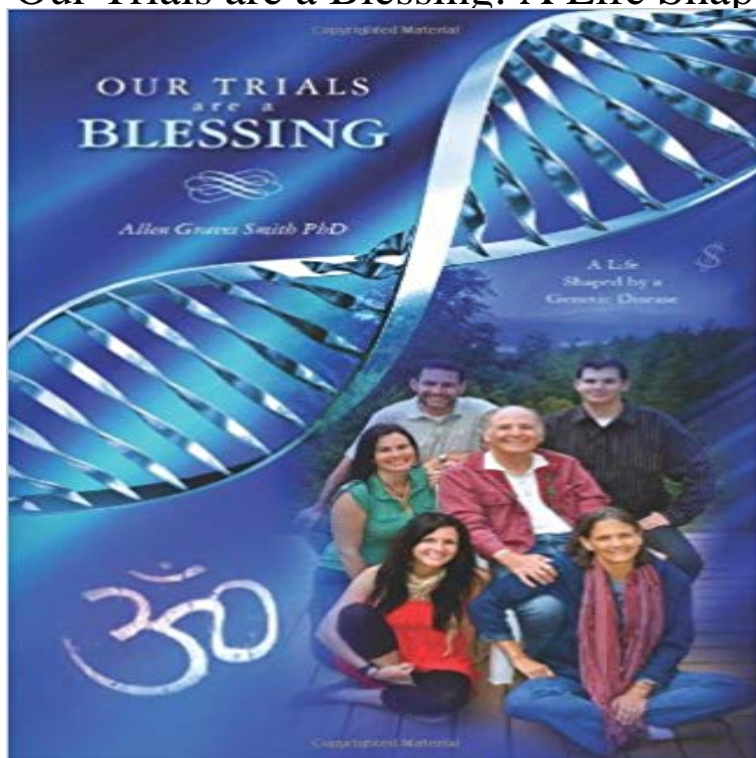


Our Trials are a Blessing: A Life Shaped by a Genetic Disease



From the Preface: I read somewhere that Natalie Wood had a life-long fear of dark, deep ocean water - right up to the night she drowned off Catalina Island. I don't know if that is true, but I do know that I had a life-long fear of ending up in a wheelchair like my uncle. This despite all the doctors' assurances at the time that my uncle's condition was spontaneous and non-hereditary. They were technically correct; my condition is not the same as my uncle's. It is, though, similar in its effects. But that is not the end of the story. Nor is it the beginning. My condition (Friedreich's Ataxia) is not my life. Instead, it provides a backdrop or matrix for all that I am and all that I've done, a platform on which the events of my life have unfolded. At times, especially in the early years, that background was distant, and even irrelevant. Later, it became overwhelming and psychologically paralyzing. More recently, it has faded into the background once again, even though its effects are more pronounced and debilitating. I wouldn't say that it has become a welcome friend, but (to torture a metaphor) it has become an appreciated companion and a valued teacher. My life and attitudes have been shaped but not blunted by the ataxia. I don't want this to be a man conquers affliction tale. In fact, if I could live my life over again, without the ataxia, I don't think I would. That's not to say I wouldn't welcome a magical cure today that would arrest or reverse its effects. But I wouldn't undo the role my condition has played in shaping me. And that is the story I want to tell.

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