

## BOOK REVIEW

### **Testing Fate: Tay-Sachs Disease and the Right to be Responsible** *by Shelley Z Reuter*

Hardback, 288 pages  
University of Minnesota Press  
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As a paediatrician I have come across and managed many cases of Tay-Sachs disease. This is a cruel neurodegenerative disorder: it kills young children after great suffering and we have no cure.

Without denying or minimising the hard realities of this condition at a medical level, Reuter compels the reader to look at the wider context within which this and other conditions are seen. Building on Foucault, amongst others, she demonstrates that the social context of disease is just as important as the medical aspect, and argues that disease must be understood as a concept with cultural and historical implications in order for there to be truly free informed choice or “agency”.

The author explores how from the late 19<sup>th</sup> Century Tay-Sachs was seen as a racialised condition of the Jewish people, within which group the overwhelming majority of such cases were found at that time. Working within the concept of responsible “biocitizenship”, educational and screening measures have virtually eliminated such cases from the Jewish community worldwide. From solely a medical perspective, reduction in the number of cases is seen as the benchmark of success.

However, Reuter demonstrates that being “a responsible biocitizen” is more complex than simply not having children with Tay-Sachs. On the flip side is “the right to responsible parenthood” and what that entails, including medical malpractice suits on behalf of children born with the condition. I found particularly thought-provoking the section on the “unethics” of looking at still or moving images (whether on YouTube or telethons) of disease-disabled children. Taken without consent, such images are a considerable intrusion upon their privacy and dignity and a form of child labour.

This book is important because it demonstrates that greater inclusiveness in medical research, paradoxically, can have exclusionary effects by solidifying pre-existing notions of biological difference and lead to “medical racialism”. Extrapolating from Tay-Sachs to other genetic and non-genetic conditions such as obesity, Reuter discusses the changing nature of biopolitics. For medical science to be effective it has to be inclusive and fully engage with the public group concerned. It must do so without any form of injustice, either direct or indirect, since bias leads to discrimination and, in practice, takes away real choice.

In *Testing Fate*, by moving beyond fundamental pathology, the author succeeds in her aim of “imagining genetic disease – and agency – differently”.

**Andrew N Williams**  
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