1.

Record Nr.	UNINA9910163282503321
Autore	Le Fanu Joseph Sheridan
Titolo	In a Glass Darkly - Volume I of III
Pubbl/distr/stampa	London : , : Copyright Group, , 2016 ©2016
ISBN	1-78543-806-9
Descrizione fisica	1 online resource (82 pages)
Lingua di pubblicazione	Inglese
Formato	Materiale a stampa
Livello bibliografico	Monografia

2.

Record Nr.	UNINA9910988295603321
Autore	Huyard Caroline
Titolo	The Social Life of Rare Disorders / / by Caroline Huyard
Pubbl/distr/stampa	Singapore : , : Springer Nature Singapore : , : Imprint : Palgrave Macmillan, , 2025
ISBN	9789819620081 9819620082
Edizione	[1st ed. 2025.]
Descrizione fisica	1 online resource (IX, 287 p.)
Disciplina	306.461
Soggetti	Social medicine Medical policy Medical anthropology Science - Social aspects Health, Medicine and Society Health Policy Medical Anthropology Medical Sociology Science and Technology Studies
Lingua di pubblicazione	Inglese
Formato	Materiale a stampa
Livello bibliografico	Monografia

Nota di contenuto	Introduction -- Part I Birth of the Rare Diseases -- Wilson’s Disease: Between Craftsmanlike and Industrial Medicine -- The Invention of Rare Diseases: Responding to the Problem of Orphan Drugs -- Part II What Does It Mean to Experience a Rare Disease? -- Experiencing Isolation -- Association as a Way Out of Isolation? -- Part III Small Groups, Big Challenges -- Who Runs the Associations? Beyond the Patient–Doctor Divide -- Building a Therapeutic Toolbox -- A Fragile Coalition of Disparate Associations -- Conclusion.
Sommario/riassunto	This is an exciting book that takes a sociological and hermeneutical perspective on ‘rare diseases’. -- Jeannette Pols, Professor Anthropology of Everyday Ethics, University of Amsterdam, The Netherlands This book offers a valuable overview of the history of rare diseases and the lived experience of people with a rare disease. -- Magorzata Rajtar, Head of the Center for Social Research on Rare Diseases, Institute of Philosophy and Sociology of the Polish Academy of Sciences, Poland This book is the first comprehensive study of rare disorders from a historical, political, and social perspective. It is estimated that around 300 million people worldwide live with a rare disorder today. What do patients and associations concerned by one of the 7,000 known rare diseases have in common, and what does rarity mean to them? How did rare disorders become a mainstream category in public health policy? To answer these questions, Caroline Huyard traces the history, over more than 50 years, of medical treatments for one particular disease, and that of the orphan drug status in the United States and in Europe. The book shows that public authorities had a much greater role than biomedicine in turning rare disorders into a public health problem. A comparison of patients' experiences of 6 rare diseases as well as the activities of 8 associations in France underlines the importance of isolation and care for patients on the one hand, and the role of stakeholders’ participation for associations on the other hand. This book is essential reading for researchers and students interested in contemporary healthcare systems and topics related to public policies on emerging issues, the industrialisation and regulation of medicine, the concept of care, and the governance of patient organisations. Caroline Huyard is a sociologist. She is a tenured researcher (Chargée de Recherches) at the Centre National de la Recherche Scientifique (CNRS) and the University of Lille, in France.