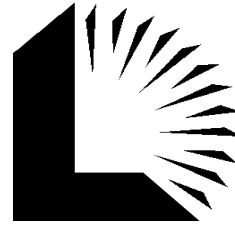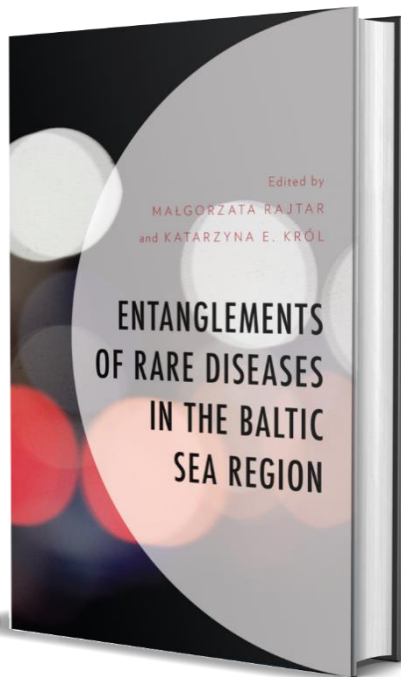NEW FROM
LEXINGTON BOOKS

ENTANGLEMENTS OF RARE DISEASES IN THE BALTIC SEA REGION

Edited by Małgorzata Rajtar and Katarzyna E. Król

This edited collection is a welcome contribution to the social science and anthropological understanding of rare disease, rare disease communities, and national policies and practices. Its focus on the Baltic Sea region is original, and through a series of case studies, each chapter chronicles a local context which has global resonance. The book attends to a wide range of social science topics, including biosociality, relationships, diagnostic work, resilience, expertise, health tourism, stigma, identity and norms of rareness, illness, and disability. It also acknowledges the often difficult experiences of patients and patient communities. In doing so, it both recognizes, and represents, the nuances and complexities of rare disease. Overall, this edited collection provides a data-rich and comprehensive overview which benefits from a broad authorship, including academics across multiple disciplines, students, practitioners, and patient advocates.

—Rebecca Dimond, Cardiff University

Entanglements of Rare Diseases in the Baltic Sea Region provides in-depth analysis of the experiences families face in caring for and understanding the needs of those experiencing "orphan" illnesses. Utilizing ethnographic insights and survey data, contributors push theoretical understandings of "chronic homework" and what it means to be considered "rare." An important collection documenting transnational immigration in search of supportive care as well as unique family-based interventions in an understudied region.

—Nancy Burke, University of California, Merced

ABOUT THIS BOOK

Although rare diseases have captured public attention in recent decades, the lived experiences of people affected by these conditions remain on the periphery of medical anthropological inquiry. Focusing on Poland, Finland, and Sweden, and foregrounding notions of "rare" or "chronic" disease as an embedded category, this book critically analyzes entanglements between people and families with rare diseases and care practices that involve local healthcare policies, practitioners, and treatment modalities. Drawing on locally grounded case studies, *Entanglements of Rare Diseases in the Baltic Sea Region* constitutes a unique and important contribution to both global medicine and social science scholarship.

ABOUT THE EDITORS

Małgorzata Rajtar is associate professor and head of the Rare Disease Social Research Center at the Institute of Philosophy and Sociology of the Polish Academy of Sciences.

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