

REPS

Fall 2023

Research Ethics and Policy Series



Book Talk: Amy Dockser Marcus

We the Scientists: How the Rise of Patient-Led Research is Changing Medicine

Amy Dockser Marcus

Author

Staff Reporter, Wall Street Journal

Patients are no longer leaving science to the scientists. They are collecting and analyzing their own medical data, using the internet to find and connect online with other groups, and conducting their own research projects. Patient-led research plays an important and expanding role in the search for new therapies, particularly in diseases that are rare or overlooked by the medical and business communities.

Amy Dockser Marcus, a Pulitzer Prize-winning reporter for the Wall Street Journal, spent years following a group of parents and scientists that worked together to develop a drug to treat a fatal and rare genetic disease. She will talk about the findings in her new book, *We the Scientists*, the rise of citizen science, and the ethical, social, and scientific challenges that emerge when patients, families, clinicians, and scientists set out to work as partners in the search for cures.



the
orphan
disease center

Co-sponsored by the Orphan Disease Center, University of Pennsylvania

Wednesday, November 8, 2023 12:00–1:00 PM

Location: (Hybrid) RCH B102AB, Richards Building, 3700 Hamilton Walk

Registration required for in-person and virtual attendance: [Register REPS Marcus](#)

Information: Lisa Bailey, Lisa.Bailey@pennmedicine.upenn.edu

REPS is co-sponsored by

