

Drawing the Line: A Documentary Screening and Discussion of the Challenges of Regulating Rare Disease Drugs



LOCATION SUNY Downstate Health Sciences
University Public Health Academic Building
(PHAB) 450 Clarkson Avenue, Brooklyn, NY 11203

DATE Monday, May 12th, 2025, 2-5 PM

NO ORDINARY CAMPAIGN



Following a viewing of the film "For Love & Life: No Ordinary Campaign", Dr. Thomas Wallach, Research Director in Pediatric Gastroenterology at Downstate is joined by Holly Fernandez Lynch, JD, MBE, Associate Professor, Medical Ethics and Health Policy, Perelman School of Medicine at UPenn and additional faculty for a discussion on the intersection between advances in bioscience research, patient interest, and regulatory entities such as the FDA.

AGENDA

2:00 PM -2:10 PM

Welcome

Speaker: Dr. Thomas Wallach MD

2:10 PM - 3:30 PM

Screening: " For Love and Life; No Ordinary Campaign

Description: : A deeply moving documentary illustrating the transformative power of love, hope and activism. The film follows Brian Wallach and his wife Sandra after his ALS diagnosis at age 37. Anchored by a deep love for each other, and empowered by their shared political prowess, they lead a revolutionary movement to change a broken healthcare system for patients of neurodegenerative diseases.

3:30 PM -4:15 PM

FDA, Regulation, and Adaptation to Modern Science

Speaker: Holly Fernandez Lynch:

4:15 PM -4:25PM

Break

4:25 PM - 5 PM

Discussion Panel and Small Group Discussions: How do we balance patient needs, the science, and protecting patients, the system, and the economy.

FACULTY

Holly Fernandez Lynch, JD, MBE Associate Professor of Medical Ethics and Health Policy, Perelman School of Medicine at UPenn



Dr. Thomas Wallach MD
Chief of Pediatric Gastroenterology
SUNY Downstate Health Sciences University