

Welcome to our session, Hijacking Patient Empowerment.

I'm Celia Wexler, your moderator.

I'm a former journalist, now a public interest advocate for the Center for Science and Democracy at the Union of Concerned Scientists. I've spent the past five years focused on improving transparency and accountability at the FDA.

It's my pleasure to introduce today's dynamite panel. Our experts will explore how patients lose their power over decisions about their health care, and how they can get that power back. I'll introduce each of them, they'll give a presentation, engage in a lively conversation, and then we'll open it up to your questions.

Before we start, I'd like to see a show of hands. How many physicians, nurses, and other health care experts are in the audience? How many of you are grassroots activists or concerned patients?

To my left is Rosemary Gibson

In her work as a policy expert, Rosemary has opened up treatment rooms and operating theaters, illuminating for all of us how medical decisions are made, often to the detriment of patients.

She's a leading authority on health care in the United States, and currently serves as an editor for the *Journal of the American Medical Association's* publication, *Internal Medicine*.

During her 16-year tenure at the Robert Wood Johnson Foundation, she helped lead a successful effort to establish palliative care in more than 1600 hospitals in the U.S, earning her a Lifetime Achievement Award from the American Academy of Hospice and Palliative Medicine.

She worked with Bill Moyers on the PBS documentary, "On Our Own Terms," which showed more than 20 million viewers how the U.S. health care system can better care for seriously ill patients.

Her books include *Wall of Silence*, telling the human story behind the Institute of Medicine report on medical mistakes, *The Treatment Trap*, which puts a human face on overtreatment, and soon to be published, *Medicare Meltdown*, examining the business of Medicare.

Today, she will be focusing on the conclusions in her 2012 book, *The Battle Over Health Care*, which draws parallels between the health care industry and the banking sector, demonstrating that the same weaknesses that nearly destroyed our financial system also weaken our delivery of health care.

Welcome Rosemary.

Dr. John Powers is a physician/investigator and an associate clinical professor of medicine at George Washington University's School of Medicine. I've known John for many years, and he is a passionate advocate for patient safety, and a trusted source of knowledge about the worrisome problem of antibiotic resistance. His expertise is well earned, having served as the lead medical officer at the FDA, overseeing the agency's work on clinical trials and policy in antimicrobial research, and spearheading inter-agency efforts to combat antimicrobial resistance. Prior to joining the FDA, John was an assistant professor in the Division of Infectious Diseases at the University of Maryland School of Medicine, where he still serves on the faculty. John also treats patients weekly in clinic and attends on the infectious diseases service. He earned his medical degree from Temple University School of Medicine, where he also served as Chief Resident. He completed his infectious diseases training at the University of Virginia School of Medicine, and is board certified in internal medicine and infectious diseases.

John will be exploring the vexing question of how the FDA decides the amount of risk patients are willing to tolerate, and whether patients understand the risks inherent in drugs and devices, even after they are approved by the FDA.

Our last panelist is **Thea Cacchioni**, an Assistant Professor in Women's Studies at the University of Victoria, previously on the women's studies faculty at the University of Warwick in Great Britain. Dr. Cacchioni is a sociologist who studies the way the health care industry and physicians have "medicalized" women's sexual response and failure to experience sexual pleasure. Thea testified before an FDA advisory panel, urging the agency not to approve the drug, Flibanserin, a daily anti-depressant nicknamed the pink Viagra. The maker of the drug marketed it as a treatment for what they termed 'hypo-active sexual desire disorder' or, lack of sexual desire, in pre-menopausal women, despite its 'unsexy' side effects of nausea, fatigue and

dizziness. In 2010, Thea held the Ruth Wynn Woodward Chair in Gender, Sexuality, and Women's Studies at Simon Fraser University in Canada. As Chair, she organized and convened "The Medicalization of Sex" conference, an international interdisciplinary event that explored the variety of ways in which science, medicine, and the pharmaceutical industry have intervened in the area of sexuality. In 2012, she co-edited a special issue of The Journal of Sex Research with Leonore Tiefer, the co-organizer of this conference. Her most recent publications deal with the medical understanding and treatment of women's sexual pain.

Thank you all for participating in this important discussion.

What struck you all about your respective presentations?

Rosemary – should there be a different, more holistic approach to address the systemic failures in our health care system?

John: What the questions patients ought to be asking their doctors to make sure their health care priorities are being addressed?

Thea: The FDA ended up not approving Flibanserin. Why? Lessons to be learned from that fight?