

Conférence exceptionnelle

Vendredi 15 décembre de 14 heures à 17 heures

à l'Espace éthique, Hôpital Saint-Louis AP-HP, 1 avenue Claude Vellefaux, 75010 Paris
(Carré historique, porte 9, 1^{er} étage)

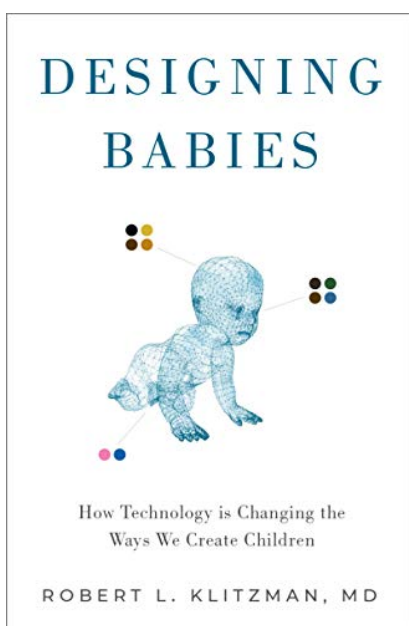


Robert Klitzman

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14h Introduction Fabrice Gzil, codirecteur de l'Espace éthique Île-de-France
Martin Dumont, responsable de la Chaire de philosophie de l'Hôtel-Dieu

14h10 Présentation et discussion de l'ouvrage
Designing Babies : How Technology is Changing the Ways We Create Children



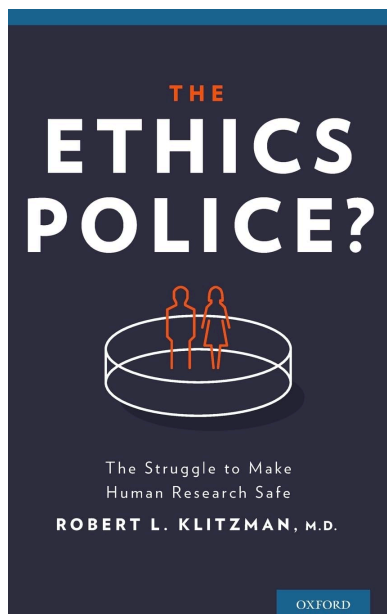
Since the first "test tube baby" was born over 40 years ago, In Vitro Fertilization and other Assisted Reproductive Technologies (ARTs) have advanced in extraordinary ways, producing millions of babies. An estimated 20% of American couples use infertility services to help them conceive, and that number is growing. Such technologies permit thousands of people, including gay and lesbian couples and single parents, to have offspring. Couples can now transmit or avoid passing on certain genes to their children, including those for chronic disease and, probably sometime soon, height and eye color as well. Prospective parents routinely choose even the sex of their future child and whether or not to have twins. The possibilities of this rapidly developing technology are astounding-especially in the United States, where the procedures are practically unregulated and a large commercial market for buying and selling human eggs is swiftly growing. New gene-editing technology, known as CRISPR, allows for even more direct manipulation of embryos' genes.

As these possibilities are increasingly realized, potential parents, doctors, and policy-makers face complex and critical questions about the use-or possible misuse-of ARTs. *Designing Babies* confronts these questions, examining the ethical, social, and policy concerns surrounding reproductive technology. Based on in-depth interviews with providers and patients, Robert Klitzman explores how individuals and couples are facing quandaries of whether, when, and how to use ARTs. He articulates the full range of these crucial issues, from the economic pressures patients face to the moral and social challenges they encounter as they make decisions which will profoundly shape the life of their offspring. In doing so, he reveals the broader social and biological implications of controlling genetics, ultimately arguing for closer regulation of procedures which affect the lives of generations to come and the future of our species as a whole.

15h20 Pause café

15h40 Présentation et discussion de l'ouvrage

The Ethics Police? The Struggle to Make Human Research Safe



Research on human beings saves countless lives, but has at times harmed the participants. To what degree then should government regulate science, and how? The horrors of Nazi concentration camp experiments and the egregious Tuskegee syphilis study led the US government, in 1974, to establish Research Ethics Committees, known as Institutional Review Boards (IRBs) to oversee research on humans. The US now has over 4,000 IRBs, which examine yearly tens of billions of dollars of research -- all studies on people involving diseases, from cancer to autism, and behavior. Yet ethical violations persist.

At the same time, critics have increasingly attacked these committees for delaying or blocking important studies. Partly, science is changing, and the current system has not kept up. Since the regulations were first conceived 40 years ago, research has burgeoned 30-fold. Studies often now include not a single university, but multiple institutions, and 40 separate IRBs thus need to approve a single project. One committee might approve a

Study quickly, while others require major changes, altering the scientific design, and making the comparison of data between sites difficult.

Crucial dilemmas thus emerge of whether the current system should be changed, and if so, how. Yet we must first understand the status quo to know how to improve it. Unfortunately, these committees operate behind closed doors, and have received relatively little in-depth investigation. Robert Klitzman thus interviewed 45 IRB leaders and members about how they make decisions.

This book reveals what Klitzman learned, providing rare glimpses into the conflicts and complexities these individuals face, defining science, assessing possible future risks and benefits of studies, and deciding how much to trust researchers -- illuminating, more broadly, how we view and interpret ethics in our lives today, and perceive and use power.

PLAN DE L'HÔPITAL SAINT-LOUIS

