SUFFOLK UNIVERSITY LAW REVIEW

VOLUME XXVII WINTER, 1993 NUMBER 4

INTERNATIONAL SYMPOSIUM ON LAW AND SCIENCE AT THE CROSSROADS: BIOMEDICAL TECHNOLOGY, ETHICS, PUBLIC POLICY, AND THE LAW

Preface
Moral Debate and Semantic Sleight of Hand
Am I My Brother's Keeper?
Predictive Genetics and the Construction of the Healthy Ill
Legal and Medical Implications of Fetal Tissue Transplantation
French, European, and International Legislation on Bioethics
Justification for Permitting Life Insurers to Continue to Underwrite on the Basis of Genetic Information and Genetic Test Results
The "New" Genetics: From Research to Reality
Public Policy and Legal Issues Raised by Advances in Genetic Screening and Testing
Abortion to Obtain Fetal Tissue for Transplant
Rethinking Medical Confidentiality: The Impact of Genetics
International Perspectives on Ethics and Human Genes

SYMPOSIUM PROCEEDINGS

LEGISLATIVE MODELS

Genetic Testing, Access to Genetic Data, and Discrimination: Conceptual Legislative Models
Organ Donation as National Service: A Proposed Federal Organ Donation Law
The Regulation of Fetal Tissue Transplantation: Different Legislative Models for Different Purposes

NOTE

Human Genes Without Functions: Biotechnology Tests the Patent Utility Standard
PREFACE

The growth of an educational institution is often measured by the degree of its involvement in matters of social concern and public policy. Measured by such a standard, the international symposium, held on October 21 and 22, 1993, Law and Science at the Crossroads: Biomedical Technology, Ethics, Public Policy, and the Law, represents a major achievement for the Law School and signals the commitment of our institution to apply legal education to the difficult task of shaping law and public policy confronted by new biomedical discoveries and technology.

Medical, scientific, and technological advances regarding organ and tissue transplantation, scientifically assisted human reproduction, mapping of the human genome, and somatic and germ line therapies are challenges to basic principles of confidentiality, consent, and allocation of medical resources without the assistance of — and some would say without interference from — legal theorists and policy makers. Equally profound is the effect of such discoveries upon ethical principles and moral choices which are fundamental to our legal system. Compulsory organ donation saves lives, but begs the question how a society defines death for purposes of such mandatory extraction. Cryogenic preservation of frozen embryos enhances reproductive options, but leaves open the limits of the property rights and the dispositional authority of each parent in the event of divorce or death. Genetic testing is now a reliable method of identifying certain gene disorders such as Huntington's Disease, but does not resolve the question whether a social purpose is advanced by encouraging or even requiring such tests where no cure is yet available and the impact of the results may prejudice the employment and insurance options of asymptomatic individuals and entire families. With each medical and technical advance comes a concomitant moral, ethical, and ultimately legal problem that requires the infusion of legal principles of the sort which have historically guided free societies to protect the rights of individuals, as well as to advance broader social interests.

The need to initiate a cross disciplinary discussion among scientists, legislators, jurists, legal scholars, and ethicists to begin to solve some of the public policy and ethical dilemmas arising from advances in bio-
medicine served as the incentive for the Symposium. In one of the first efforts of its kind at a major law school, participants were brought together from across the United States, France, Australia, Canada, Holland, and Israel to consider the impact of such advances upon law and public policy.

The efforts of those who assembled are reflected in this Symposium edition of the Suffolk University Law Review. Contained in these pages are the articles of a disparate group of distinguished authors from the fields of science and medicine, private industry, law, government, and academia. These writings express the conflicts, contradictions, and concerns which were aired during the Symposium regarding the public policy debate which has exploded in the areas of organ and tissue transplant, scientifically assisted reproduction, and genetic testing and therapy.

The articles of the major presenters at the Symposium are followed by edited transcripts of the panels. By including the panelist’s and presenter’s comments as they were made, we have been able to place in stark contrast the different views of the participants within the context of the proceedings. The final component of the Symposium material contained in this volume consists of articles prepared by faculty members responsible for structuring the content of the Symposium: Professors Linda Fentiman, Stephen Hicks, and this writer. These articles are based upon hypothetical statutes in the three areas of major focus at the Symposium: organ donation and transplant, fetal tissue research, and genetic testing and discrimination. The purpose of our articles is not to provide finished models for legislative adoption, but rather to provoke further discussion among policy makers regarding matters of current discussion and contention, including consent, confidentiality, public and scientific purpose, allocation of resources, and discrimination.

Both the Symposium and this edition of the Law Review are firsts for Suffolk University Law School. For the accomplishment of these landmark events, a debt of gratitude is owed to the Deans of the Law School, including former Dean Paul Sugarman, and Dean John F. Fenton, Jr., for their support of these projects and recognition of the important role of law schools in the emerging area of biomedicine and biomedical technology. Together with the Deans, thanks is owed to former Associate Deans Russell Murphy and Charles Kindregan for their tremendous effort in assisting with the organization of the Symposium, as well as to current Associate Deans John Deliso and William Corbett for recognizing the continuing need to include biomedical law and public policy in the Law School curriculum and the Symposium edition of the Law Review. The Symposium could not
have been organized and conducted without the tireless efforts of Carole Wagan, Director of Advanced Legal Studies at the Law School. Without her sound advice and practical guidance, this major accomplishment would not have become a reality. Finally, to my colleagues, Linda Fentiman and Stephen Hicks, sincerest thanks. Without their insight, the form and substance of the Symposium would not have taken shape as it did, providing to the participants and to those reading this volume a clear view of the public policy challenges which must be faced as biomedical advances shape our world — as well as the role of law in assisting in the solutions to those challenges.

The editors and staff of the Suffolk University Law Review have assembled a volume that we believe reflects the immediate importance of biomedical advances to the law, ethics, and public policy. It is our hope that this work will serve as a guidepost to lawyers, jurists, legislators, ethicists, scientists, and physicians whose task it will be to meet the social challenges of the new biomedicine.

Professor Barry Brown
May 9, 1995