

Gene Technology

The Impact on the Human Dimension

Edited by
Felix Unger

edition weimar

European Academy of Sciences and Arts
Edited by Ludwig Tavernier and Felix Unger

Scientific Board

Gilbert Fayl, Maximilian Fussl, José Luis Garcia Garrido,
Nikolaus Lobkowitz, György Pethes, Francisco José Rubia Vila, Raoul A. Weiler

Eugen Biser, Josef Bugl, Erich Hödl, Norbert Höslinger, Konrad Meßmer,
Erwin Möde, Peter Koslowski, Edgar Morscher, Justin Stagl,
Raphael Vara Thorbeck, Peter A. Wilderer,
Karl Matthias Woschitz

The European Academy of Sciences and Arts
is supported by the Republic of Austria and the European Union

Felix Unger (Ed.)

Gene Technology

The Impact on the Human Dimension

edition weimar
2004

edition weimar

European Academy of Sciences and Arts
Edited by Ludwig Tavernier and Felix Unger

Volume 3

Felix Unger (Hg.)
Gene Technology
The Impact on the Human Dimension

Responsible for the contents are the authors of the contributions.
Verantwortlich für den Inhalt sind die Verfasser der Beiträge.

© VDG ■ Verlag und Datenbank für Geisteswissenschaften ■ Weimar 2004

All rights reserved.

No part of this publication may be translated,
reproduced, stored in a retrieval system,
or transmitted in any form or by any means,
electronic, mechanical, photocopying, recording or otherwise,
without the prior permission of the publisher.

Reihengestaltung: Katharina Hertel, Weimar
Druck: VDG

ISBN 3-89739-382-4

Inhaltsverzeichnis

GEBHARD FÜRST

Introduction 9

OTFRIED HÖFFE

Die Moral als Preis der neuzeitlichen Forschung 13

DIETRICH VON ENGELHARDT

**Medicine between Technology and Humanity Concepts of Disease,
Therapy and Physician-Patient Relationship in the Historical Perspective** 24

Introduction 24

Antiquity 26

Middle Ages 28

Modern Times 30

Perspectives 33

Literature 35

WERNER ARBER

Roots, Potential and Conjectural Risks of Gene Technology* 36

Abstract 36

Introduction 36

Background knowledge 37

Major components of gene technology 38

Research strategies of classical genetics and of molecular genetics differences 39

The impact of genetic engineering on biotechnology 41

Conjectural risks of genetically modified organisms 42

Bacterial genetics reveals the process of molecular evolution at work 43

Products of evolution genes together with nongenetic elements

generate spontaneous genetic variations 46

Conclusions and outlook 47

References 50

FRANK GLEESON

Recent Techniques in Analyzing Genomes 51

THOMAS R. WEIHRAUCH

Impact of Pharmacogenetics on Health Care and Health Economics	60
Abstract	60
1. SHORT VERSION	61
Key stakeholders	62
2. LONG VERSION	62
Underlying assumptions and drivers	63
Increased demands on health care	63
Increased demands of the patient	64
Finite health care resources	64
Opportunities	64
For the patient	65
For the physician	65
For economic benefit	66
For the health care industry	66
Predictive medicine	68
Challenges, issues and future impact	68
Health care policy	68
Societal and ethical considerations	69
Implementation	70
Communication and education	70
Conclusion and outlook	72

J. C. HUBER

Stehen die Biowissenschaften vor einer kopernikanischen Wende?	73
---	----

DAVID C. RUBINSZTEIN

The Genetics of Alzheimer's Disease-Perspectives and Promises	80
Introduction	80
Genes causing early-onset Adapp	81
Presenilin genes	82
Apo E and Ad	83
Conclusions	86
Acknowledgements	86
References	87

SAVIO L.C. WOO

Gene Therapy: The use of Genes as Medicine	91
References	98

RUTH DEECH	
The Regulation of Therapeutic Cloning and Preimplantation Genetic Diagnosis in the U.K.	100
HORST SEIDL	
Anthropologische und ethische Überlegungen zur Gentechnologie	110
Methodologische, interdisziplinäre Vorbemerkung, anthropologische Grundlagen	112
Die biologischen Tatsachen der embryonalen Genese in naturphilosophischer und anthropologischer Perspektive	116
Zur ethischen Beurteilung gentechnologischer Eingriffe in den Embryo	117
Abschließende Bemerkung über das rechte Verhältnis des Menschen zur Natur	121
K. DIERICKX, H. NYS, I. DREEZEN, C. TROUET	
Informed Consent to take, Preserve and Use DNA Samples for Research	124
Introduction	124
Part I: Information which precedes the consent to take, preserve and use biological samples for quality assessment/research.	125
The sample	125
Supply to third parties of cell lines created by using your sample	126
Examples	126
Protection of your identity and privacy	127
Inventions, patents and commercial applications	128
Part II Consent form to take, preserve and use tissue samples for quality assessment /research	129
EUGEN BISER	
Human Dignity in Context with our Cultures	131
Die Fehlsteuerung	131
Die Überforderung	131
Das utopische Zeitalter	132
Der Rückbezug	133
Das Zeitgeschehen	135
Die Kompetenz	137
Die Berechtigung	138
Schlussbemerkung	140

EDGAR MORSCHER	
Does Gene Technology Endanger the Autonomy of Human Beings?	142
BEAT SITTER-LIVER	
Responsibility in Gene Technology: The Impact of Human Finitude	148
The need for common goals and some difficulties tied to it	148
The importance of the hermeneutical approach in biomedical ethics	149
Finitude: a repressed condition of human existence	151
Authenticity in gene technology	153
Finitude and moral responsibility	156
Conclusion	159
GÜNTER VIRT	
Die Spaltung des Menschlichen im Horizont der modernen Lebenswissenschaften	160
Ethische Vorbemerkungen	161
Das jüdisch-christliche Menschenbild	163
Methodischer Frageraster,	165
Das reduktionistische Menschenbild	168
HEINZ SCHOTT	
Alchemie versus Gentechnologie: Ärztliche Ethik bei Paracelsus und ihre Aktualität	174
1. Dimension: Das göttliche Gebot	175
2. Dimension: Die ärztliche Kunst	176
3. Dimension: Die Heilkraft des Arztes	177
Ausblick auf Gentechnologie und Bioethik heute	179
Literatur	182
FRANZ CARDINAL KÖNIG	
Die Erschaffung des Menschen	183

Introduction

GEBHARD FÜRST

Thank you for your kind invitation to open this workshop. I should like to express my pleasure that as an institution, the European Academy of Sciences and Arts, which represents and brings together outstanding scientists and academics, has chosen this key topic for discussion. Within your own scientific fields, many of you deal with current bio-ethical questions whether from the perspective of natural sciences or the arts.

This is also a signal to the public that will not be overlooked. Many of you are directly involved in the challenges and come face to face with the dilemmas posed by the new discoveries and technology, whether as doctors, researchers, politicians, moral philosophers or jurists. You bear responsibility, but responsibility needs standards and orientation. Therefore, it is important that we enter into a dialog about the bio-ethical questions.

Current developments in genetic engineering and bio-medicine are resulting in profound changes to culture and civilization. Never before have we known so much, never before have we been able to achieve what we can achieve today. But do we want to know everything that we can know? And should we do everything we can do, just because we can? I represent the Catholic German Conference of Bishops on the recently founded National Council for Ethics, which aims to reflect the ethical questions and arguments in connection with life sciences. The Church, ladies and gentlemen, must assert its convictions about man and his dignity, about the right social, economic and state order in society's discourse. It considers itself an advocate of humanity and the inviolability of man.

Today, this aspect of inviolability that actually distinguishes human beings is threatened by secondary aims, an issue that has been highlighted several

times by the Catholic Church, most recently in Germany in the paper entitled "Man his own creator?" and by the Central Committee of German Catholics. Does man not collapse under the contradiction that he plays God over life and death of his fellow human beings and at the same time thinks so poorly of himself that he regards human life only as biological material to be exploited? Especially where ethical questions are concerned, the Church represents not only a large group of society but an ethical competence which has developed over many centuries in discussion with the most diverse cultures and is ultimately the modern basis of morality. In terms of the current bio-ethical questions, transnational standards and orientation are needed, to which the Church will make its contributions, because of its history and its belief in itself as worldwide, universal Church. The Church supports genetic engineering and bio-medicine where it respects and fosters the dignity of man; but the Church must highlight the risks and consequences.

The basis of Christian ethics is the dignity of the human being that stems from being created in God's own image. This human dignity is enshrined in the German Basic Law, the jurisdiction of the Federal Constitutional Court and the constitutions of most European countries. Every human being has the right to absolute human dignity, inviolable by other human beings or by the state. Human dignity can neither be earned nor lost. It cannot be made dependent on performance, happiness, social tolerance or similar assessed by a third party. It is just as absurd at the basic level as it is arbitrary at the concrete level to tie human dignity and the entitlement to protection under the law to a person's performance. I cannot convince anybody to respect my dignity, if that person does not respect my dignity by simply taking me seriously as the other person in a discussion. When human life is in the position of having to justify its existence, we are on a slippery slope, not just at the beginning but also at the end of life. Human dignity and the human condition are indivisible because the development of man and the condition of being human are a continuous organic process from the fusion of the ovum and sperm cell, through embryonic life and birth, through childhood and

adulthood to illness, dying and death. Neither science nor anthropology provide an authentic, evidence-based turning point in human development that is independent of any value judgment. The church is not defending a nostalgic idea of life but one of the moral basic principles of the Enlightenment. It is concerned that these principles have become irrelevant and dispensable in favor of economic profit, in the modern and ostensibly enlightened societies.

Secondly, the principle of human dignity means that man must be the aim and purpose of all social and scientific developments, but must never be used as the means to that end. Whatever experiments are carried out in the name of science and technology, especially in medicine and pharmacology, must be proven to serve the well-being of mankind and successive generations. Evidence must be provided as to why research and application should be carried out, not as to why it should not be done or on the basis that it might be useful and might not cause harm. In this point, the current discussion is suffering from broken promises of happiness and fantasies of salvation as well as from the complete uncertainty of short and long-term consequences of this new technology. Just as “therapeutic cloning” has nothing to do with therapy but with cultivation of human biological material, the pre-implantation diagnosis has less to do with helping childless couples but more to do with avoiding sick and handicapped children. It is a paradox when research and technology that wants to serve man consumes human life. Research, enabled by a loophole in the law, with imported stem cells is only the first step towards destroying the laws that protect embryos. In fact, genetic engineering, just as nuclear energy in its time, has caused more problems than it has solved.

Thirdly, it is part of absolute human dignity that human life must be taken seriously in terms of its moral character. In other words, just as the individual has the right not only to be a product of genetic engineering but also to be a child of his parents, so conversely parenthood is not only concerned with producing a descendant of as high a genetic quality as possible but is an

expression of a moral and social relationship. Human beings are reproduced and not created. Children are not goods where you can claim for damages when they are faulty. It is a cruel imposition on a man to have to live with the awareness that he was chosen because of certain promising genetic aptitudes for life and having to develop appropriately.

Mr. President, ladies and gentlemen, what I have just presented are the central points in the ethical orientation of questions of bio-medical research and application. Let me in conclusion point out one more issue from my experiences in the political discourse as it has been held up to now. We are all called upon to form a responsible opinion about these crucial bio-ethical questions, each and every citizen, but especially scientists, academics, and those who bear the responsibility for our community and for our culture, particularly political and legal culture in Europe.

In the past, the Catholic Church has demanded a wider, more transparent, and greater public debate of these issues. In the meantime, such a discussion has started and we, I, welcome that. However, there is another important point. Ethics cannot be delegated to scientific ethics centers or to national ethics councils or ethical committees in hospitals or anywhere else. Responsibility cannot be represented in this way. Ethical councils will certainly not simply give a green or red light to certain problems, as some politicians have intended. An ethical council does not function like traffic lights where you have to stop at the red light and move forward on green, and race across quickly when its yellow. What it is about though, is collecting all the important information, facts and ethical and moral arguments in order to enable those with responsibility to form an autonomous and proper opinion. This workshop will surely play an important part. Ladies and gentlemen, Mr President, I wish you much success.