The Ethics of Human Gene Therapy


Overall rating: Excellent
Strengths: Easily understood, concise description of science, techniques and possible uses of gene therapy; listing of ethical issues from a clinical ethics perspective
Weaknesses: Little analysis of the collective effects of the use of gene therapy on shaping social attitudes and practices; incomplete discussion of social and ethical issues
Audience: Health professionals, research ethics committee members, general public

The authors’ purpose was to describe the science of gene therapy and to examine the major ethical questions. Toward the end of the volume, they state that their mission has been accomplished if they have stimulated the reader to think about these possibilities in a calm and rational way and to reach their own judgment. Most of the 153 pages of text and the 43 pages of appendices focus on describing and illustrating the current and potential uses of gene therapy. There are useful summaries of guidelines and opinion surveys.

The authors, a philosopher and an attorney, introduce genes and heredity in the first chapter. The next three chapters discuss somatic and germ-line therapy, and enhancement genetic engineering, and a fifth chapter considers public policy. Each chapter begins with a clear, well-illustrated discussion of historical developments and builds to the current developments.

Technical advantages are clearly described, without ethical assessment. For instance, the advantages of germ-line over somatic therapy are described as more effective when the disease 1) affects many different organ systems and disparate cell types (e.g., cystic fibrosis); or 2) is expressed in nonremovable and nondividing cells (e.g., Lesch–Nyhan syndrome). Of course, germ-line therapy is also effective beyond the individual, with the therapeutic effect passed on to subsequent children and a possible reduction of certain inherited diseases in the human gene pool. Technical discussions are followed by an evaluation of ethical arguments. Generally speaking, the authors take a permissive stance with respect to somatic and germ-line therapy and toward enhancement genetic engineering.

Their ethical discussions are probably the weakest point in the volume. The technical discussions receive about twice as much discussion as the ethical, and the approach is implicitly utilitarian. The authors admit that their analysis is shaped by their assumptions about health (species-typical function or improved function) and human nature (dissatisfaction with the human condition). Their fascination with the details of the technologies seems to connote a bold embrace of genetic technologies without evaluation of alternatives. It is curious that the authors of such a historically and technologically grounded account seem to lack the humility and sense of fallibility that lead other authors to more cautious conclusions. For instance, they conclude: “Genetic enhancements are an important part of the overall task of attempting to provide a better life and a better world to our descendants.”

Overall, the volume is well written and readable for anyone who has taken a college or high school biology course. It will certainly stimulate reflection by interested physicians, members of research ethics committees, or members of the general public. Ethical reflection would benefit from supplemental reading through the perspective of feminist writers and persons with disabilities.

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Slow Dance: A Story of Stroke, Love and Disability


Overall rating: Good
Strengths: Important insights into the challenges of stroke survivors
Weaknesses: Fewer “characters” analysed in greater detail might have had more impact
Audience: Health care professionals, stroke patients and their families

This book is a narrative account by its author, an award-winning documentary NFB filmmaker, of survival and partial recovery from a brainstem hemorrhage. It can be
emotional hurdles faced by the au-
standing of the many physical and
will benefit from a better under-
reactions to this book. But everyone
health care workers will have varying
problems with the US health care
without insurance as an example of
. . . the list goes on.
Feldenkrais, Alexander technique
paper cranes, meditation tapes,
ture, quartz crystals, folded Japanese
for alternative therapies: acupunc-
a connection.
Discouraging to readers without such
rules for your care.” This may be
[her husband] made up his own
it. In the words of a friend: “Michael
by those who know their way around
how the system can be manipulated
through each new day.
There are varying examples of
how the system can be manipulated
by those who know their way around
it. In the words of a friend: “Michael
[Klein’s husband] made up his own rules for your care.” This may be
discouraging to readers without such
a connection.
The story includes their search
for alternative therapies: acupuncture,
quartz crystals, folded Japanese
paper cranes, meditation tapes,
Feldenkrais, Alexander technique
. . . the list goes on.
She tells the story of a US stroke
patient who struggled on her own
without insurance as an example of
problems with the US health care
system. It invites speculation: How
different would Klein’s story have
if she had to trade places?
Physicians, patients, feminists and
health care workers will have varying
reactions to this book. But everyone
will benefit from a better under-
standing of the many physical and
emotional hurdles faced by the au-

thor. Osler was right: “Listen to the
patient.”

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(see the Jan. 1, 1997, issue for Klein’s
husband’s experience and how he chal-
lenged the medical profession to rethink
its views toward the physician as family
member (page 53). — Ed.)

Books and other media received

Livre et autres documents reçus

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Endocrinology: Basic and Clinical
Principles. Edited by P. Michael Conn
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Comprehensive Assessment of Mortal-
ty and Disability from Diseases, In-
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Projected to 2020. Edited by Christo-
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Global Burden of Disease and Injury Series,
vol. 1. 990 pp. Illust. World Health Or-
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0-674-35448-6

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Saunders Review of Family Practice.
2nd ed. Edited by Edward T. Bope, Alvah
Illust. W.B. Saunders Company/Harcourt
Brace and Company, Philadelphia; W.B.

Health care

An Inventory of Quality Initiatives in
Canada: Maintaining and Improving
Quality in Health Care. 2nd ed. Edited
Canada. 307 pp. Health Canada, Ottawa;
ISBN 0-662-24978-X. (Includes inven-
tory of Internet sites relevant to quality in
health care issues. Also available online
[www.hwc.ca] or on computer diskette
or audiocassette, or in large print or
braille. Egalement disponible en français.)

History

Jean I. Gunn: Nursing Leader. Natalie
Regler. Hannah Institute for the History
of Medicine Series: Canadian Medical Lives.
Fitzhenny and Whiteside, Markham, Ont.
1997. $18.95. ISBN 1-55041-175-6

Neurology

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rology, Neurosurgery, and Psychiatry
books. 911 pp. Illust. BMJ Publishing Group,
London. 1997. Distributed in Canada by
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tawa. $137.95 (US$114.95 CMA members).

Pharmacology

Goodman and Gilman’s The Pharma-
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Surgery

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David Crawford and Christopher Koo.
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dam. 1996. Price not stated. ISBN 90-
5702-007-6 (single user licence); ISBN
90-5702-006-8 (site/institution licence)