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Ethics and Genetics

A Workbook for Practitioners and Students

Genetic information plays an increasingly important role in ourlives. As a result of the Human Genome Project, knowledge ofthe genetic basis of various diseases is growing, withimportant consequences for the role of genetics in clinicalpractice, health care systems and for society at large. In theclinical setting genetic testing may result in a better insightinto susceptibility for inheritable diseases, not only before orafter birth, but also at later stages in life. Besides prenataltesting and pre-conceptional testing, predictive testing hasresulted in new possibilities for the early detection, treatmentand prevention of inheritable diseases. However, not all inheritable diseases that can be predicted onthe basis of genetic information can be treated or cured.Should we offer genetic tests to people for untreatablediseases? Should we test every individual who wants to knowhis or her genetic status? Should we inform family membersabout the results of genetic tests of individuals, even whenthere are no possibilities for treatment? What, in such cases,is the role of the "right-not-to-know"? Should we informfamily members when there is only an increased risk of adisease? This book deals with the ethical issues of clinicalgenetics, as well as ethical issues that arise in geneticscreening, the research of populations, and the use of geneticinformation for access to insurance and the workplace.

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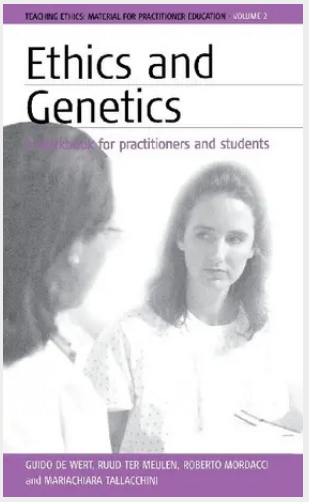

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