

Essay: Genetic Discrimination: Balancing Privacy and Genetic Information.

Title: Genetic Discrimination: Balancing Privacy and Genetic Information

Introduction:

The rapid advancements in genetic research and the availability of genetic testing have opened up new possibilities for understanding and managing health conditions. However, these developments have also raised concerns about the potential for genetic discrimination. Genetic discrimination refers to the unfair treatment of individuals based on their genetic

Genetic Discrimination And Genetic Privacy In A Comparative Perspective Ius Commune Europaeum

Graeme T. Laurie



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Genetic Discrimination and Genetic Privacy in a Comparative Perspective Janneke H. Gerards, A. W. Heringa, Heleen L. Janssen, 2005 During the last decades a better understanding of the influence of genetic factors on the onset of illness and disease has evolved Unfortunately however the information revealed by genetic tests is not always accurate and reliable and its probabilistic value is often limited Throughout the world the possibility of genetic testing and the availability of individual genetic information have therefore caused increasing social concern especially since many actors outside the medical profession such as health and life insurance companies and employers have shown a growing interest in individual genetic information In many states as well as on the international level there is an ongoing debate about the balance that should be struck between the protection of the individual against misuse of genetic information and the interests of social actors and genetic research institutes and about the policy options that are at hand to reduce the risks that are created by the availability of genetic information This book offers some clarity as to the choices that have been made in various legal systems both national and international with respect to the regulation of genetic information On the basis of an elaborate analysis of relevant legislation policy approaches and case law in the United States the various European states and on the international level the book aims to provide insight in the issues that must be deemed relevant in considering and eventually introducing regulative measures with respect to genetic information *Judicial Lawmaking and Administrative Law*, 2005 The book before carries a broad title In the Dutch literature the terms lawfinding and lawmaking are often used interchangeably From a legal point of view however it makes quite a difference to the position of the court whether lawfinding or lawmaking is meant Why write a book about lawmaking by the courts just in the area of administrative law In administrative law the administration is positioned between the legislature and the judiciary The courts review decisions taken by the administration in implementing the law however where the administration has often been granted a degree of discretion the courts assess the lawfulness of the decision The relation administration judiciary raises so many specific questions that it justifies a book on judicial lawmaking in administrative matters The authors are all members of the research program Public Law of the Ius Commune School *European Journal of Social Security*, 2004 **European Traditions in Civil Procedure** C. H. van Rhee, 2005 European co operation has resulted in many new and challenging opportunities for legal scholars who since the so called codification period have become used to operating in a purely national context This applies also to scholars in the field of civil procedure who for a considerable period of time have resisted leaving the purely national domain These scholars have devoted a great deal of attention to the question whether or not harmonisation of civil procedural law is a feasible option and if so in what manner harmonisation should be achieved The contributors to this book seek to further the harmonisation debate by exploring some of the main trends in the development of civil procedural law during the last two centuries in several European countries Germany Austria Switzerland France England and Wales The

Netherlands and Belgium Two of the central issues that are addressed by the contributors are the extent to which the various procedural models have influenced each other and the extent to which common traditions in civil procedural law may be distinguished in Europe Each general chapter in this book is supplemented by three chapters devoted to specific procedural topics Conciliation Party Interrogation as Evidence and the Role of the Judge In addition extensive bibliographical references are included

Current Publications in Legal and Related Fields, 2006 Towards a Unified System of Land Burdens? Bram Akkermans, 2006 Various legal systems were discussed Austria Belgium England France Germany the Netherlands Scotland and the United States The leading theme was whether civil law systems can learn from the Anglo American experience Particularly the American Law Institute's Restatement Third of Property Servitudes offers an interesting model for unification

Gehuwd of niet--maakt het iets uit?, 2005 Genetic Discrimination Gerard Quinn, Aisling de Paor, Peter Blanck, 2014-11-20 As genetic technologies advance genetic testing may well offer the prospect of detecting the onset of future disabilities Some research also forwards that certain behavioural profiles may have a strong genetic basis such as the determination to succeed or the propensity for risk taking As this technology becomes more prevalent there is a danger that genetic information may be misused by third parties and that particular genetic profiles may be discriminated against by employers by providers of social goods and services such as insurance companies and even by educational facilities This book explores the different forms and potential uses of genetic testing Drawing together leading experts in disability law bioethics health law and a range of related fields it highlights the ethical and legal challenges arising as a result of emerging and rapidly advancing genetic science On examining transatlantic perspectives on the matter chapters in the book ask whether the US Genetic Information Nondiscrimination Act GINA is proving to be an effective tool in addressing the issue of genetic discrimination and alleviating fears of discrimination The book also reviews what insights may be gained from GINA within employment and health insurance contexts and asks how the UN Convention on the Rights of Persons with Disabilities CRPD may impact similar debates within the European Union The book focuses particularly on the legislative and policy framework in the European Union with an emphasis on the gaps in protection and the scope for specific legislative action in this area This book will be of great interest to scholars and students of discrimination law bioethics and disability law and will be of considerable use to legal practitioners medical practitioners and policy makers in this area

Genetic Testing and the Governance of Risk in the Contemporary Economy Lara Khoury, Adelle Blackett, Lukas Vanhonnaeker, 2020-10-01 This book addresses emerging questions concerning who should bear responsibility for shouldering risk as well as the viability of existing and experimental governance mechanisms in connection with new technologies Scholars from 14 jurisdictions unite their efforts in this edited collection to provide a comparative analysis of how various legal systems are tackling the challenges produced by the legal aspects of genetic testing in insurance and employment They cover the diverse set of norms that surround this issue and share insights into relevant international

regional and national incursions into the field. By doing so the authors offer a basis for comparative reflection including on whether transnational standard setting might be useful or necessary for the legal aspects of genetic testing as they relate to the insurance and employment contexts. The respective texts cover a broad range of topics including the prevalence of genetic testing in the contexts of insurance and employment and policy factors that might affect this prevalence such as the design of national health or social insurance systems of private insurance schemes or the availability of low cost direct to consumer genetic testing. Further the field of genetics is gaining in importance at the international and regional levels. Relevant concepts mainly genetic tests and genetic data information have been internationally defined and these definitions have influenced definitions adopted nationally. International law also recognizes a special status for human genetic data. The authors therefore also consider these definitions and the recognition of the special status of human genetic data within regional and national legal orders. They investigate the range of norms that specifically address the use of genetic testing in employment and insurance encompassing international sources including human rights norms that may be binding or non binding as well national statutory regulatory and soft law mechanisms. Accordingly some of the texts examine general frameworks relevant to genetic testing in each country including those that stem from general anti discrimination rules and norms protecting rights to autonomy self determination confidentiality and privacy. In closing the authors provide an overview of the efficiency of their respective legal regimes approaches specific and generalist to genetic testing or disclosure of genetic information in the employment or insurance contexts including the effect of lack of legal guidance. In this regard some of the authors highlight the need for transnational action in the field and make recommendation for future legal developments.

Genetic Privacy: An Evaluation Of The Ethical And Legal Landscape Terry Sheung-hung Kaan, Calvin Wai-loon Ho, 2013-07-04. Privacy is an unwieldy concept that has eluded an essentialised definition despite its centrality and importance in the body of bioethics. The compilation presented in this volume represents continuing discussions on the theme of privacy in the context of genetic information. It is intended to present a wide range of expert opinion in which the notion of privacy is examined from many perspectives in different contexts and imperatives and in different societies with the hope of advancing an understanding of privacy through the examination and critique of some of its evolving component concepts such as notions of what constitute the personal the context of privacy the significance and impact of the relational interests of others who may share the same genetic inheritance and mechanisms for the protection of privacy as well as of their limitations among others. More specifically the discussions in this volume encourages us to think broadly about privacy as encompassing values that are entailed in the sociality of context and of relations and also as freedom from illegitimate and excessive surveillance. A long standing question that continues to challenge us is whether genetic information should be regarded as exceptional as it is often perceived. A conclusion that could be derived from this volume is that while genetic information may be significant it is not exceptionally so. The work presented in this volume underlines the continuing and

growing relevance of notions of privacy to genomic science and the need to take ownership of a genetic privacy for the future through broad rigorous and open discussion Contributors Alastair V Campbell Benjamin Capps Jacqueline JL Chin Oi Lian Kon Kenji Matsui Thomas H Murray Nazirudin Mohd Nasir Dianne Nicol Anh Tuan Nuyen Onora O'Neill Margaret Otowski Yvette van der Eijk Chunshui Wang Ross S White

Genetic Data and the Law Mark Taylor, 2012-03-08 Research using genetic data raises various concerns relating to privacy protection Many of these concerns can also apply to research that uses other personal data but not with the same implications for failure The norms of exclusivity associated with a private life go beyond the current legal concept of personal data to include genetic data that relates to multiple identifiable individuals simultaneously and anonymous data that could be associated with any number of individuals in different but reasonably foreseeable contexts It is the possibilities and implications of association that are significant and these possibilities can only be assessed if one considers the interpretive potential of data They are missed if one fixates upon its interpretive pedigree or misunderstands the meaning and significance of identification This book demonstrates how the public interest in research using genetic data might be reconciled with the public interest in proper privacy protection

Genetics, Disability and the Law Aisling de Paor, 2017-09-21 With genetic technologies advancing rapidly Aisling de Paor examines the urgent need for an EU level framework to regulate genetic information

Genes and Insurance Marcus Radetzki, Marian Radetzki, Niklas Juth, 2003-11-06 The result of two key social developments in recent years are examined here the partial dismantling of the welfare state and the progress of genetics Genetic insights are increasingly valuable for risk assessment and insurers would like to use these insights to help determine premiums Combined with the fact that social welfare is being curtailed this could potentially create an uninsured high risk population Along with considerations of autonomy and privacy this is the basis for an ethical critique of insurer's access to information The result has often been regulation of such information but the authors argues that due to adverse selection regulation will not solve these problems and this may jeopardize the survival of private personal insurance Instead we should look towards the resurrection of social insurance a key component of the welfare state This will interest academic researchers as well as professionals involved with genetics and insurance

Genetic Privacy and Discrimination Eugene Oscapella, 2012-01-01

Genetic Privacy Graeme Laurie, 2002-05-16 The phenomenon of the New Genetics raises complex social problems particularly those of privacy This book offers ethical and legal perspectives on the questions of a right to know and not to know genetic information from the standpoint of individuals their relatives employers insurers and the state Graeme Laurie provides a unique definition of privacy including a concept of property rights in the person and argues for stronger legal protection of privacy in the shadow of developments in human genetics He challenges the role and the limits of established principles in medical law and ethics including respect for patient autonomy and confidentiality This book will interest lawyers philosophers and doctors concerned both with genetic information and issues of privacy it will also interest genetic counsellors researchers and policy

makers worldwide for its practical stance on dilemmas in modern genetic medicine

Perspectives on Genetic

Discrimination Thomas Lemke, 2013-07-18 Over the past 15 years a series of empirical studies in different countries have shown that our increasing genetic knowledge leads to new forms of exclusion disadvantaging and stigmatization The spectrum of this genetic discrimination ranges from disadvantages at work via problems with insurance policies to difficulties with adoption agencies The empirical studies on the problem of genetic discrimination have not gone unnoticed Since the beginning of the 1990s a series of legislative initiatives and statements both on the national level and on the part of international and supranational organizations and commissions have been put forward as ways of protecting people from genetic discrimination This is the first book to critically evaluate the empirical evidence and the theoretical usefulness of the concept of genetic discrimination It discusses the advantages and limitations of adopting the concept and offers a more complex account distinguishing between several dimensions and forms of genetic discrimination Privacy, Confidentiality

and Discrimination in Genetics United States. Congress. House. Committee on Commerce. Task Force on Health Records and Genetic Privacy, 1998

Genetic Discrimination Leana J. Albertson, 2008 Genetic information can be misused It can be used to discriminate against people in health insurance and employment People known to carry a gene that increases their likelihood of developing cancer for example may get turned down for health insurance Without health insurance it may be impossible for some people to get treatment for a disease that could be fatal This may lead some people to decide against genetic testing for fear of what the results might show and who might find out about them It also could lead some people to decline participation in biomedical research such as studies of gene mutations associated with certain diseases that examine the history of families prone to those maladies This new book examines some of the hot areas of research in the field

Genetics Policy Report Alissa Johnson, Cheye Calvo, 2002 Genetic Privacy Graeme T. Laurie, 2002 The phenomenon of the New Genetics raises complex social problems particularly those of privacy This book offers ethical and legal perspectives on the questions of a right to know and not to know genetic information from the standpoint of individuals their relatives employers insurers and the state Graeme Laurie provides a unique definition of privacy including a concept of property rights in the person and argues for stronger legal protection of privacy in the shadow of developments in human genetics He challenges the role and the limits of established principles in medical law and ethics including respect for patient autonomy and confidentiality

Embracing the Beat of Term: An Emotional Symphony within **Genetic Discrimination And Genetic Privacy In A Comparative Perspective Ius Commune Europaeum**

In a global eaten by monitors and the ceaseless chatter of instantaneous conversation, the melodic elegance and emotional symphony produced by the prepared word frequently fade into the background, eclipsed by the constant noise and distractions that permeate our lives. But, situated within the pages of **Genetic Discrimination And Genetic Privacy In A Comparative Perspective Ius Commune Europaeum** a charming literary treasure overflowing with natural emotions, lies an immersive symphony waiting to be embraced. Crafted by an elegant musician of language, that interesting masterpiece conducts readers on a mental trip, skillfully unraveling the concealed songs and profound influence resonating within each cautiously crafted phrase. Within the depths of this emotional examination, we can examine the book is central harmonies, analyze its enthralling publishing design, and submit ourselves to the profound resonance that echoes in the depths of readers souls.

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