

MAPPING FATE

A MEMOIR OF
FAMILY, RISK,
AND GENETIC RESEARCH



ALICE WEXLER

Mapping Fate A Memoir Of Family Risk And Genetic Research

Jenni Ogden



Mapping Fate A Memoir Of Family Risk And Genetic Research:

Mapping Fate Alice Wexler, 1996-12-30 Wexler tells the story of a family at risk for Huntington's disease a hereditary incurable fatal disorder from which her own mother died This graceful and eloquent account goes beyond the specifics of the disease to explore the dynamics of family secrets of living at risk and the drama and limits of biomedical research Photos

The Drama of DNA Karen H. Rothenberg JD, MPA, Lynn Wein Bush PhD, MS, MA, 2014-03-14 Through the use of dramatic narratives *The Drama of DNA* brings to life the complexities raised by the application of genomic technologies to health care and diagnosis This creative pedagogical approach shines a unique light on the ethical psychosocial and policy challenges that emerge as comprehensive sequencing of the human genome transitions from research to clinical medicine Narrative genomics aims to enhance understanding of how we evaluate process and share genomic information and to cultivate a deeper appreciation for difficult decisions encountered by health care professionals bioethicists families and society as this technology reaches the bedside This innovative book includes both original genomic plays and theatrical excerpts that illuminate the implications of genomic information and emerging technologies for physicians scientists counselors patients blood relatives and society In addition to the plays the authors provide an analytical foundation to frame the many challenges that often arise

Neurogenetic Diagnoses Carole H. Browner, Mabel H. Preloran, 2009-12-18 As world populations continue to age the incidence of very common ultimately fatal neurodegenerative diseases some of medicine's most puzzling illnesses will increase exponentially *Neurogenetic Diagnoses the Power of Hope and the Limits of Today's Medicine* explores the diverse impacts and intense meanings of genetic diagnoses for patients suffering from such diseases and for their family caregivers and clinicians Through richly textured often heart wrenching longitudinal case studies *Neurogenetic Diagnoses* reveals how extremely difficult it can be for patients to obtain a definitive diagnosis for the cause of their symptoms even with genetic testing how with or without definitive diagnoses patients and family caregivers strive to come to terms with their situations and how they are aided or not in these endeavors by their doctors The analysis is framed by increasingly sharp social debate over the consequences of decoding the human genome and the impact of genetic technology on our lives

The Drama of DNA Karen H. Rothenberg, Lynn W. Bush, 2014 Through the use of dramatic narratives *The Drama of DNA* brings to life the complexities raised by the application of genomic technologies to health care and diagnosis This creative pedagogical approach shines a unique light on the ethical psychosocial and policy challenges that emerge as comprehensive sequencing of the human genome transitions from research to clinical medicine Narrative genomics aims to enhance understanding of how we evaluate process and share genomic information and to cultivate a deeper appreciation for difficult decisions encountered by health care professionals bioethicists families and society as this technology reaches the bedside This innovative book includes both original genomic plays and theatrical excerpts that illuminate the implications of genomic information and emerging technologies for physicians scientists counselors patients blood relatives and society In

addition to the plays the authors provide an analytical foundation to frame the many challenges that often arise *The Gene* Siddhartha Mukherjee, 2016-05-17 The 1 NEW YORK TIMES Bestseller The basis for the PBS Ken Burns Documentary *The Gene: An Intimate History* Now includes an excerpt from Siddhartha Mukherjee's new book *Song of the Cell* From the Pulitzer Prize winning author of *The Emperor of All Maladies* a fascinating history of the gene and a magisterial account of how human minds have laboriously ingeniously picked apart what makes us tick Elle Sid Mukherjee has the uncanny ability to bring together science history and the future in a way that is understandable and riveting guiding us through both time and the mystery of life itself Ken Burns Dr Siddhartha Mukherjee dazzled readers with his Pulitzer Prize winning *The Emperor of All Maladies* in 2010 That achievement was evidently just a warm up for his virtuoso performance in *The Gene: An Intimate History* in which he braids science history and memoir into an epic with all the range and biblical thunder of *Paradise Lost* The New York Times In this biography Mukherjee brings to life the quest to understand human heredity and its surprising influence on our lives personalities identities fates and choices Mukherjee expresses abstract intellectual ideas through emotional stories and swaddles his medical rigor with rhapsodic tenderness surprising vulnerability and occasional flashes of pure poetry The Washington Post Throughout the story of Mukherjee's own family with its tragic and bewildering history of mental illness reminds us of the questions that hang over our ability to translate the science of genetics from the laboratory to the real world In riveting and dramatic prose he describes the centuries of research and experimentation from Aristotle and Pythagoras to Mendel and Darwin from Boveri and Morgan to Crick Watson and Franklin all the way through the revolutionary twenty first century innovators who mapped the human genome A fascinating and often sobering history of how humans came to understand the roles of genes in making us who we are and what our manipulation of those genes might mean for our future Milwaukee Journal Sentinel *The Gene* is the revelatory and magisterial history of a scientific idea coming to life the most crucial science of our time intimately explained by a master *The Gene* is a book we all should read USA TODAY **Human Genetics: The Basics** Ricki Lewis, 2010-10-06 Human genetics has blossomed from an obscure branch of biological science and occasional explanation for exceedingly rare disorders to a field all of its own that affects everyone Human Genetics *The Basics* introduces the key questions and issues in this emerging field including The common ancestry of all humanity The role of genes in sickness and health Debates over the use of genetic technology Written in an engaging narrative manner this concise introduction is an ideal starting point for anyone who wants to know more about genes DNA and the genetic ties that bind us all Methods in Medical Ethics Jeremy Sugarman, Daniel P. Sulmasy, 2001 Twenty four American specialists provide descriptions of techniques critiques and notes on resources and training on a variety of methods used in medical ethics Individual chapters are devoted to each of 11 methods philosophy religion and theology professional codes legal methods casuistry history qualitative ethnographic quantitative surveys experimental methods and economics and decision science Discussion includes how these methods can relate to one another and how to assess the quality of

scholarship in medical ethics in connection with such issues as physician assisted suicide euthanasia and medical genetics For scholars teachers editors and students in all disciplines contributing to the field c Book News Inc *Moments of Truth in Genetic Medicine* M. Susan Lindee,2008-11-24 Genetic research increasingly dominates medical thought and practice in the United States and in many other industrialized nations Susan Lindee s original study explores the institutions disciplines and ideas that initiated the reconfiguration of genetic medicine from a marginal field in the mid 1950s to a core research frontier of biomedicine Tracing the work of geneticists and other experts in identifying and classifying disease during the explosive period between 1950 and 1980 Lindee identifies the individual moments of truth that moved the field away from its eugenic past to the center of a new world view in which nearly all disease is understood to be fundamentally genetic She suggests that these moments of truth were experienced not only by scientists but also by those who had familial intimate emotional knowledge of hereditary disease patients family members and research subjects Focusing on benchmarks in the field such as the rise of neonatal testing in the 1960s genetic studies of unique human populations such as the Amish the development of human cytogenetics and human behavioral genetics and the efforts to find genes for rare diseases such as familial dysautonomia she tracks the emergence of a biomedical consensus that nearly all disease is genetic disease Using the success of this field as a point of entry Lindee chronicles both the production of knowledge in biomedicine and changes in the cultural meaning of the body in the late twentieth century She suggests that scientific knowledge is a community project that is shaped directly by people in many different social and professional locations The power to experience and report scientific truth may be much more dispersed than it sometimes appears because people know things about their own bodies and their knowledge has often been incorporated into the technical infrastructure of genomic medicine Lindee s pathbreaking study shows the interdependence of technical and social parameters in contemporary biomedicine

Signifying Bodies G. Thomas Couser,2009-10-22 Sheds new light on the memoir boom by asking Is the genre basically about disability Memoirs of Well-Being Tanja Reiffenrath,2016-05-15 As the body politics of life writing in the United States change illness and disability memoirs receive considerable attention Although these narratives are framed by a lack of health they abundantly present health and do so beyond its binary relationship to the pathological This book departs from previous scholarship by bringing into focus the writers representations of cure recovery and healing as well as their reluctance to bring closure to their narratives and align their stories with traditional notions of health These memoirs thus partake in the construction of alternative narratives of illness and disability **No Easy Choice** Ellen Painter

Dollar,2011-11-01 In **No Easy Choice** Ellen Painter Dollar tells her gut wrenching story of living with osteogenesis imperfecta OI a disabling genetic bone disorder that was passed down to her first child and deciding whether to conceive a second child who would not have OI using assisted reproduction Her story brings to light the ethical dilemmas surrounding advanced reproductive technologies What do procedures such as in vitro fertilization IVF and preimplantation genetic diagnosis PGD

say about how we define human worth If we avoid such procedures are we permitting the suffering of our children How do we identify a good life in a consumer society that values appearance success health and perfection Dollar considers multiple sides of the debate refusing to accept the matter as simply black and white Her book will help parents who want to understand and make good decisions about assisted reproduction as well as those who support and counsel them including pastors and medical professionals

Huntington's Disease Clay Farris Naff,2012-06-12 Huntington's Disease causes degeneration of brain cells in motor control regions of the brain as well as other areas Symptoms get progressively worse and include uncontrolled movements abnormal body postures and changes in emotion behavior judgment and cognition People with HD also develop impaired coordination slurred speech and difficulty feeding and swallowing Provide your readers with essential information on HD This book also serves as a historical survey by providing information on the controversies surrounding its causes Compelling first person narratives by people coping with Huntington's Disease give readers a first hand experience Patients family members or caregivers explain the condition from their own experience The symptoms causes treatments and potential cures are explained in detail Essential to anyone trying to learn about diseases and conditions the alternative treatments are explored Student researchers and readers will find this book easily accessible through its careful and conscientious editing and a thorough introduction to each essay

The Book of Life Barbara Katz Rothman,2001-04-19 The much heralded completion of the human genome project in the year 2000 raises urgent questions Do we now have a map of who we are How will we control the uses of the potentially healing but also likely destructive and highly marketable information genetics brings us Using her own life as well as her research Barbara Katz Rothman presents an impassioned defense for the theory that humans are not ready made from the factory as one recent popular book on genetics put it but social beings who grow mature and learn who they are

Trouble in Mind Jenni Ogden,2012-02-02 In *Trouble in Mind* clinical neuropsychologist Jenni Ogden recounts with compassion insight and vivid description the stories of patients who as the result of brain damage begin thinking and behaving strangely As they struggle to make sense of their disordered minds they teach everyone around them about courage and determination and what it is to be human

Reading Autobiography Sidonie Smith,Julia Watson,2010 projects and an extensive bibliography Book Jacket

[Biosocialities, Genetics and the Social Sciences](#) Sahra Gibbon,Carlos Novas,2007-07-20 This pioneering collection uses Paul Rabinow's concept of biosociality to chart the shifts in social relations and in ideas about nature biology and identity brought about by developments in biomedicine

Eradicating deafness? Marion Andrea Schmidt,2020-04-20 How did American geneticists go from fearing the dysgenic effects of deaf intermarriage to considering modern biotechnology a threat for Deaf culture This book provides insight into changing ideas of what deafness is what science and medicine should achieve and to the transformative effect of exchange between scientists and deaf communities

Achieving Justice in Genomic Translation Wylie Burke MD, PhD,Kelly A. Edwards PhD,Sara Goering PhD,Suzanne Holland PhD,Susan Brown Trinidad MA,2011-09-15

This book explores implicit choices made by researchers policy makers and funders regarding who benefits from society's investment in health research The authors focus specifically on genetic research and examine whether such research tends to reduce or exacerbate existing health disparities Using case examples to illustrate the issues the authors trace the path of genetics research from discovery through development and delivery to health outcomes Topics include breast cancer screening and treatment autism research pharmacogenetics prenatal testing newborn screening and youth suicide prevention Each chapter emphasizes the societal context of genetic research and illustrates how science might change if attention were paid to the needs of marginalized populations Written by experts in genetics health and philosophy this book argues that the scientific enterprise has a responsibility to respond to community needs to assure that research innovations achieve much needed health impacts *NINDS at 50* Lewis P. Rowland, 2001

The Human Genome Project in College Curriculum Aine Donovan, Ronald Michael Green, 2008 Begun formally in 1990 the U S Human Genome Project's HGP goals were to identify all the 20 000 to 25 000 genes in human DNA determine the sequences of the three billion chemical base pairs that make up human DNA store this information in databases improve tools for data analysis and transfer related technologies to the private sector It was the first large scientific undertaking to address potential issues that arose from project data and opened up vast possibilities for the use of genetic data and the alteration of our genetic makeup This volume is the first to address the diverse range of ethical issues arising from the HGP and enables professors to bring this critically important topic to life in the classroom

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